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The Family's Voice: Caregiving for an Older Adult

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The Family's Voice: Caregiving for an Older Adult

by

Deborah J. Mason, B.S.W., LSW

MSW Clinical Research Paper

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

Master of Social Work

Committee Members

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

Abstract

The purpose of this research was to explore the family as a unit, in particular the effects on the multigenerational family when at least one person is giving care to an adult over the age of 65. While, most prior research focused on the caregiver, this study looked at family as a whole single unit. The respondents were asked to describe how the caregiving affected them personally as well as how it affected the family.

The sample for this study included 16 adult family members of caregivers for a person over age 65. Data was collected utilizing an online survey. Respondents were recruited with the assistance of local senior assisted living and apartment communities and by some postings in local social work groups.

Respondents voiced that life was now stressful and frustrating. Although some revealed there were benefits, many stated the caregiving affected the family in an adverse way. This study confirmed the idea that having a family member caring for an older adult member does affect the dynamics of the whole family.

Acknowledgments

I would like to thank my professor and research committee chair, Dr. Abel Knochel for all the support, patience, and guidance offered through this research process. The unwavering encouragement I received and continual support served to motivate me to continue and successfully complete, what at times seemed like an overwhelming and endless task.

I am also immensely grateful for my research committee members, Emily Samsel and Mary Morrison, for taking time away from family to carefully review my work and offering their encouraging words of support. The social work experience and assistance offered by both greatly influenced my ability to complete this study. Appreciation is also offered to The Alton Memory Care, Golden Living Center, and The Wellington Senior Living centers for their assistance recruiting volunteers and to the volunteers who participated in the survey.

Huge wholehearted thanks to my children and grandchildren for encouraging me to follow my childhood dream of obtaining a college education. Without their support and understanding, and taking over our family holiday dinners, the time away from them would have been unbearable. I am also appreciative of my employer, Pinnacle Services Inc. for supporting me and allowing me the time off when necessary to complete this.

Most of all, I am thankful to the St Catherine University/ University of St Thomas' School of Social Work, for my excellent education. This program and my participation in The Area of Emphasis on Aging area provided me with the skills and knowledge to move my career in social work forward.

Personal Reflective Statement

I am an Area of Emphasis on Aging (AEA) scholar and a practicing licensed social worker, currently working with clients aged 65 and up as a case manager. Given my interest in family and the older adult population, it is only natural that my research is centered on this populace. Subsequently, my research focused on families that include a caregiver to an older adult and how, if at all, this affects the family. I concentrated on the family as a whole unit, rather than the individual caregiver or older adult.

My work as a case manager is to assess and assist the older adult, ensuring they are receiving the services needed to help them stay safe and healthy. I meet with older adults and their families in the older adult's home. Home can be the house they lived in for years, a senior apartment, an assisted living facility, or the home of the family member. Sometimes we will meet in a hospital or a nursing facility. During these meetings, I will often hear comments about how stressed the family is, and how the caregiver never sees his/her own children or spouse due to the time needed with their older parent. As a result of these and other comments, I decided to explore the family side of caring for an older adult member. My hope was to learn more about what the family needs are and to possibly recognize ways that as a social worker I can best meet the clinical needs of the older adult and their family.

Last year, my step mom fell ill and was also the victim of financial elder abuse. My family went through some frustrating times. Subsequently, because I am the eldest of ten surviving children and a licensed social worker who works within the older adult population, my siblings looked to me for answers. I, of course, did not have answers and the suggestions I offered did not meet with everyone's satisfaction. Although my family

went through some difficult weeks, the majority of us were able to come together to find the best possible resolution for both our mom and the family.

My primary career objective is to be able to support the family unit emotionally and psychologically, while allowing the older adult to remain within the family structure in the best possible way for his or her own family. I anticipated and expected that, through this study, I would identify some ideas and methods to accomplish this.

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Introduction

In a scenario which is seen all too often, the aging parent, Mom and/or Dad, needs support and assistance. The adult child begins to contemplate this new and often foreboding situation. What can I do? I work fulltime. I have children of my own. I am a single parent. I barely make ends meet now. I am so tired, as I already work two jobs. How am I going to manage? How will this affect my family? These are just a few of the questions adult children face as their parents begin to age and need support.

Nearly 40 billion people in the United States are considered to be part of the aging population, and by the year 2030 there will be 70 million people over 65 years of age (United States Government, Administration on Aging, [AOA], 2010). The United States Government has projected that 67 percent of this number will be over 85 years of age by 2030 (United States Government, Administration on Aging, [AOA], 2010). Before 1980, less than 1 percent of the total population of the United States was over 85, yet by the year 2050 the number is predicted to be over 4 percent (AOA, 2010). This is an alarming increase for families and society to comprehend.

There are over 65 million caregivers providing care to someone who is ill, disabled or aged in the United States (Coughlin, 2010). The Alzheimer's Association (2011) found that there are 43.5 million family members caring for people over 50 years of age, nearly 15 million of whom were caring for someone with Alzheimer's disease or another type of dementia. Current caregivers must also concern themselves with parents that have a prolonged longevity of life, which is a socio-historical factor never experienced in past generations (Rice & Fineman, 2004). Given these changing demographics, Fingerman, Hay, KampDush, Cichy, & Hosterman, (2007) have

established that it is no longer unusual for midlife adults to care for and support both younger and older generations.

“[T]he family has undergone tremendous change” (Bianchi & Casper, 2000, p. 1). Whiting and James (2005) define family as a diverse blending of people significant to us, often including people not related by birth. In previous generations the majority of families primarily consisted of two adults with one working fulltime, while the other stayed home to care for the needs of the family (Boorman & Kimbrel, 2011). Conversely, many current families are headed by two working adults or a single parent trying to do it all alone (Boorman & Kimbrel, 2011). Some present-day families, according to Whiting and James (2005) include adult children, grandchildren and great grandchildren living at home. Other families consist of friends living together and trying to make ends meet. These contemporary configurations of family appear to exacerbate the needs and stresses of those with older adults. Caregivers are managing the needs of two or three generations.

A family caregiver is anyone who provides any type of physical and/or emotional care to a loved one. These caregivers may include adult children, spouses, grandchildren and other family members. Caregiving responsibilities include household management, medical assistance, emotional support, daily hygiene and shopping. In fact, providing care includes just about anything the older adult needs.

Research and experience inform us that, when one individual is in trouble, it affects the whole family (Bowen, 1966; Satir, 1983). Social workers often interact with the aging person, the caregiver and the family. An increasing number of those families include more than one generation living and interacting with one another. The purpose of this research is to explore the family as a unit, in particular the effects on the

multigenerational family when at least one person is giving care to an adult over the age of 65.

Literature Review

Aging Facts

Over the last century, the aging population has increased dramatically. The US Census (2010) counted over 40 million people in the 65 and older bracket, including an estimated 5.5 million over 85 years old. According to Boorman and Kimbrel (2011), this latter group is sometimes referred to as the “oldest of the old” (p.118). Never before in history have we recorded so many oldest of the old. The US Administration on Aging (2010) predicts by the year 2030 over two percent of the population will be over age eighty-five.

The growing number in our aging population is in part credited to the baby boomer generation and the norm of larger families that was found within twentieth century American culture (US Administration on Aging, 2010). Persons in Western societies also tend to live longer today, as they are healthier than those in past generations (Stewart, Cutler, & Rosen, 2013). This increase in the aging population and longevity within old age are leading to a growing need for support and caregiving.

We know from prior research many members of our older adult population experience isolation and increased stress (Ottmann, Dickson, & Wright, 2006; Qiu et al., 2010). Social isolation, defined as lack of social interactions or loss of a network of friends for Americans over 65 years of age, has been estimated as high as 35% (Cattan, White, Bond, & Learmouth, 2005). Moreover, our elderly may experience additional aging concerns. According to Bradley et al. (2010), these may include but are not limited to; cognitive decline, dementia, physical disabilities, arthritis, heart conditions, Parkinson’s disease, or incontinence concerns.

According to Bookman and Kimbrel (2011), this “change in the elder population will present challenges to family members who help provide elder care” (p.118). Bradley et.al. (2013) noted how many of these older adult members needing care are also giving care to others who are over 80 years old. Rollins (2008) found that many of the caretakers are over 60 years old and, consequently, are facing concerns with their own decreasing physical and mental health. This intensification in health issues adds additional strain on a family caring for an older adult.

Caregivers

The majority of caregivers are women, and nearly 60 percent are also working outside the home (Boorman & Kimbrel, 2011). Most companies do not offer elder care benefits (i.e. flexible hours, work from home, paid time off), according to Boorman and Kimbrel (2011), and caring for an older parent does not reduce the number of hours worked in their job (Barnes, Given, & Given, 1995). Many caregivers are midlife adults in the process of several intergenerational transitions, as in addition to having responsibility of caring for a parent, they also have adult children either still home or due to the current economy moving back to the family home. This slower transition of children in to adulthood, according to Settersten & Ray (2010), adds concern for the middle age caregiver. These women are challenged to balance the demands of holding down a job and caring for juvenile dependents with the added burden of caring for a parent or grandparent.

International Monetary Fund (2009) identified the global economic crisis of 2008 as one factor in this current societal variation from past generations. Igarashi, Hooker, Coehlo, and Manoogian (2013) concluded that currently, the typical middle-aged couple

has more parents than children. Undoubtedly, these deviations from the former generations will have some effect on families. These changes will “present challenges to family members who help provide elder care” (Boorman & Kimbrel, 2011, p.118).

Worry and Depression

As caregivers struggle to meet the needs of the older adult, they worry about many things. Li (2005) defined four types of caregiving worry. These included “worrying about the patients [health] condition, worrying about the care received from the health care team, worry about future care provided by the family caregiver and worry about finances” (p. 3). Family caregivers also worry about the possibility that the older adult’s needs will become unmanageable, which would then necessitate a transfer of the older adult to a nursing home (Achbold & Stewart, 2005; Achbold & Stewart, 1994; Canter, 1983).

Baillie, Norbeck and Barnes (1988) established that while 32 percent to 36 percent of the caregivers professed to be depressed, in actuality the numbers were determined to be much higher, with nearly 48 percent of the caregivers experiencing some form of psychological distress. Several studies found that the longer an individual is responsible for the care of an elderly family member, the higher the occurrence of stress and the less social support the caregiver receives. Depression for these long term caregivers is also determined to be at much higher than for those who do not have this obligation (Achbold & Stewart, 2005; Achbold & Stewart, 1994; Canter, 1983).

Earlier studies regarding caregiver mental health concerns were focused primarily on depression and anxiety, yet few concentrated on how the depression and anxiety was affected by the illness of the older individual needing the care (Halm, 1990; Lenz &

Perkins, 2000). This perception of worry is found to be problematic, specifically in the family home care setting (Achbold & Stewart, 2005; Achbold & Stewart, 1994; & Canter, 1983).

Financial Concerns

The cost for care of an older adult can be exorbitantly expensive. In a survey of all 52 states, plus the District of Columbia, the hourly salary in 2012 for a home health aide ranged from a low of \$11.00 per hour to a higher end of \$35.00 an hour and nursing home rates were upwards of \$100,000 per year depending on the care needed and the type of facility (Genworth, 2012). These costs have increased immensely over the last few years and show no sign of slowing down. For example, the cost of a yearly nursing facility care is reported to have gone up an average of \$15,330 between 2007 and 2012 (Genworth, 2012).

Without access to governmental programs, many families must take this expense upon themselves. Upon examination of several comparative family studies, Cox and Soldo (2013) found finances to be of paramount concern to many elderly people and their caregivers. The Genworth's Cost of Care Survey (2012), recognized as the most complete and thorough assessment of costs, also found that identifying how to pay for these ever increasing financial costs was the families' foremost concern.

Isolation

Many members of our elder population experience isolation and increased stress (Ottmann, Dickson, and Wright, 2006; Qiu et al., 2010). Older adults, "consistently ranked relationships with family and friends second only to health as the most important area of life" (Victor et al, 2000, p. 409). Johnson and Catalano (1983) found that as the

older adult declines, they lose contact with friends, and become more dependent on the family. Johnson and Catalano (1983) found that the needs of the older adult have a “ripple effect” on the rest of the family (p. 612). Non caregivers and caregivers experience some of the same feelings of social isolation as that of the older adult (Robison, Fortinsky, Kleppinger, Shugrue, and Porter, 2009).

Family Dynamics

Numerous research studies have focused on the needs and care of an aging person, but few have examined the impact on the family as a whole. Hannum et al., (2007) identified a growing need to include the family when determining quality care for our aging population, proposing that the care should be both “patient centered” and “family focused” (p. 21). Wivell and Mara (2010) emphasized the impact caring for an elder has on family relationships by concentrating their study of elder care on the voices of the family. These family members cited culture, love, and respect as reasons to care for the older adult (Wivell & Mara, 2010). Additionally, Bowen (1971) maintained that loyalty, obligation and mutual benefit are the fundamental familial links that connect generations, and emphasized that family members of all ages are healthier when they maintain that intergenerational emotional contact.

Although families vary in their dynamics and how they interrelate with one another, Wivell and Mara (2010) found that for many families, the “predetermined patterns and dynamics continued and they did not appear to change significantly as the elder family member aged” (p.17). Illustrations that Wivell and Mara (2010) presented were the spoiled brat continued to act as a spoiled brat and the bossy child seemed to continue in this role as the person in charge. Conversely, Fingerman, et.al. (2007); and

Sands, Ferreira, Stewart, Brod, and Yaffe, (2004) found the parent and child relationship dynamic does change when the older adult's health deteriorates.

This contradiction, according to Connidis and McMullin (2002), illustrates the need for family members to discuss and navigate fresh, innovative sociological familial procedures. Connidis (2010) ascertains that this prospect for negotiation allows the family to continue as previously determined or to make changes in the family relationships and move forward. Moreover, Igarashi, Hooker, Coehlo, and Manoogian (2013) reference Hagestad (2003) and Settersten, (2009) as they assert; "Our lives and timetables are interconnected where the needs and circumstances of others in the family network influence the individual and experiences of family" (p. 5).

Our understanding of the aging population and their interaction with family can be clarified using a life-course perspective (Dannefer and Settersten, 2010). This perspective establishes that our lives are linked and thus are influenced by the plans, the pain, the struggles, and the hope of others we have relationships with. Dannefer and Settersten (2010) found that when one person's life is out of order, family relationships suffer.

Dating back to Mary Richmond (1922), case work has always included family interviews. However, it was not until the 1950s that a family centered approach came about (Bowen, 1966). According to Hartman (1995), social workers were the first to realize that the whole family was affected when one family member was suffering. The family systems theory soon developed, which viewed the individual as part of the family. Bowen (1966) declared that the family is not just a group of persons living in the same house, with each having individualist behaviors; family is also a unit. Kerr (1988)

affirmed this thought as he accentuated, “Family systems theory radically departed from previous theories of human emotion functioning by virtue of its conceptualization of the family as an emotional unit” (p. viii).

In multigenerational households, Pruchno, Burant, and Peters (1997) found that families relied more on emotionally based coping than knowledge or skill. This led to higher rates of depression for the caregiver and the family (Pruchno et al., 1997). Family counselors, according to Riley and Bowen (2005), must recognize that there is relationship between increased stress for a caregiver and its effect on the children of the caregiver. Acknowledging this caregiver stress is essential to effective family therapy.

Literature shows there are many studies that have focused on the needs of the older adult and on the caregiver; however, few have concentrated on the needs of the family as a whole. This study will focus on the families which have at least one caregiver that offers care and support for an aging member over age 65. This research will explore the needs of the multigenerational contemporary family caring for an older adult and identify ways social workers can support the entire family as a caregiving unit. Based on a review of the literature (Hartman, 1995; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009; Zhang, Kao, & Hannum, 2007) it is expected that this research will find the family also experiences the same isolation and increased stress as that of the older adult.

Conceptual Framework

The conceptual frame used for this research is the family systems model and perspective. A system, as defined by Merriam-Webster online (2013) is “a group of related parts that move or work together, a regularly interacting or interdependent group of items forming a unified whole.” According to the Bowen Center for The Study of Family, Bowen (1966) began looking at the family as a system, an “emotional unit” and uses a methodical view to describe the multifaceted connections within the unit (para.1). He found that the family is not just a group of persons living in the same house with each having individualist behaviors.

The parts (persons) in a family are interrelated beings exhibiting behaviors through the interactions among each other with each one dependent on the other (Bowen, 1966; Rooney, Rooney, & Strom-Gottfried, 2013). As identified by Rooney, Rooney, and Strom-Gottfried (2013) these interactions within a family create the whole. Rooney, Rooney, and Strom-Gottfried (2013) also assert that all families have boundaries and these boundaries act as partitions that develop subsystems within a family and amid the family’s environment.

Jones and Diamond (1982) ascertain the functionality of the family is a significant factor in managing the family member’s care. Rooney, Rooney, and Strom-Gottfried (2013) maintain that all families have rules; however, most of these rules are understood and not documented. Some families are more flexible than others, yet the rules are nonetheless passed down from previous generations. Because social work views the family as a system, we are compelled to assess the functionality of the group and “treat the family as an organizational structure that is a functioning whole” (Greene, 2008, p.

25). Jones and Diamond (1982) also enumerated that the functionality of the family is a significant factor in managing the family member's care.

According to Kerr (1997), family systems philosophy is based on the idea that families slowly change from generation to generation and, therefore, we are influenced by both current and preceding members. Consequently, family systems theory includes a multigenerational position. Likewise, Jones and Diamond (1982); Cox and Davis (1993) affirm once a family member becomes ill, and/ or enters a long term care facility, the family situation plays an important role. Ziembra (2002) surmised that illness in a family is a 'shared family event' and to keep balance in a family, all members must be considered (p. 36). This research, using the family systems theory, will explore the family as a unit, in particular the effects on the multigenerational family when at least one person is giving care to an adult over the age of 65.

Methods

Purpose of Study and Research Design

The purpose of this study was to understand the effect[s] on the family when one family member is a caregiver to an aging person. The goals for this study were to gain perspective on family dynamics as well as to discover and promote best practice for social work with families when one member is a caregiver to an aging person. For the purpose of this study, an older adult person was defined as someone who is 65 years of age or older. This study did not exclude based on gender, sexual orientation or the older person's family position. This study used an online survey to gather information from family members of a caregiver giving care to an older adult.

Sample

A targeted sampling strategy was used to recruit respondents for this study. A targeted sampling, as defined by Monette, (2010) “involves strategies to ensure the people or groups involved with specified characteristics have an enhanced chance of appearing in the sample” (p. 151). They are selected “for a theoretical reason, because they will be especially useful in gathering certain kinds of information” (Monette, 2010, p. 151).

The family members were not required to live with the caregiver yet they had to meet the following criteria:

- The respondent was both over 18 and under 65 years of age.
- The respondent was not considered to be a vulnerable adult.
- The respondent was a member of a family with at least one caregiver to an older adult over 65 years of age.
- The respondent was not the primary caregiver.

- The respondent lived in the Minneapolis – St. Paul Metro area.

Respondents were recruited with the assistance of The Alton Memory Care, Golden Living Center and The Wellington Senior Living centers, by posting a flyer and/or contacting families through emails to residents' families. The emails and flyer explained the research project, its purpose, and provided the researcher's contact information (See Appendix A). A copy of the flyer was posted and passed out (See Appendix A). Respondents were also recruited by posting a notice in the Minneapolis and St. Paul area social work group; Social Workers Allied for Problem Solving (SWAPS) on Facebook, in addition to an email to members of the Area of Emphasis on Aging Scholars Program (See Appendix B and Appendix C).

A total of 21 respondents began the survey, with 20 completing and submitting the survey. Sixteen of the respondents met all the criteria and were included in the study. Four of the completed surveys were disqualified because the respondents stated that they were the main caregiver. An additional respondent was ineligible as the respondent had exited the survey before completing the qualifying questions. These responses were not included in the final results.

Of the 16 qualified completions, two respondents stated their spouse was the main caregiver, six stated their mother was the main caregiver, and one each identified the primary caregiver as their grandmother, aunt, cousins, sister in law, uncle, or brother. Two said they hired staff to complete day-to-day caregiving tasks. All respondents had some connection to the Minneapolis- St. Paul area, either by residing here themselves or through the older adult needing care living here.

The respondents' answers were varied in describing the residence of the older adult family member. Assisted living facilities were notated as the most common place of residence with 35% selecting this, followed closely by 30% in the family home, 20% residing in a nursing facility and 10% living in their own senior apartment. The remaining respondent stated their older adult was recently deceased.

The length of time the family member had been caring for the older adult varied, with 37% stating the caregiver had been caring for the older adult for one to two years, 26% responding in the three to five year range, 26% stating more than five years and 11% answering the caregiving had been going on for less than one year. There were three respondent families with children under 18 years of age.

Data Collection Process

Respondents were provided with a survey link to participate, either by email or in the posted recruitment tools. The survey included four multiple choice, closed ended, demographic questions and space for comments. These demographic questions included who the caregiver was, did the family include small children and family status of the respondents. These were followed by six open ended questions covering the subjects of quality of family life experience, relationship with caregiver, impact of caregiving on family, and suggestions for supporting the family. Data from the online survey was organized and sorted via Qualtrics and downloaded into a word document for content analysis.

Protection of Human Participants

This study was reviewed and approved by the research committee and the St. Catherine University Institutional Review Board (IRB). Full disclosures of my identity,

the purpose for this study and data collection methodology were provided to potential respondents. All participation in the study was voluntary. All online survey respondents prior to completing the survey were given an announcement introducing the project and informing them about the type of information sought (See Appendix D).

Full and informed consent of the survey respondents was obtained electronically for participation in the online survey. An electronic signature was obtained by respondent clicking yes to confirm they had read the consent form and wished to proceed (See Appendix D). Respondents could print a copy if they wished.

Identity of survey respondents was kept confidential. No personal identifying information was used at any time during this project. Respondents in the online survey were identified by numbers rather than names to protect their confidentiality and family privacy. Respondents were not told who else participated. No names or identifying information were collected. All respondents were given the option to email the researcher for a copy of the study. The information collected was secured in a locked cabinet in my home, which only I have access to. My colleagues that assisted with coding were aware of privacy criteria and statements of confidentiality were signed by both (See Appendix F). To maintain respondent confidentiality, published results of the data do not contain information that can be used to identify the respondents.

Files were examined on the computer in the privacy of my home. No information was saved on the system and no identifying data was shared with anyone. I live alone and my computer is password protected. The research was analyzed and presented as a requirement of the St. Catherine University/University of St. Thomas Master of Social Work Program on May 20th, 2014. Per the St. Catherine University/University of St.

Thomas Master of Social Work Program policy, the completed project will be kept publicly available by the university. All identifying data, in addition to the online survey was destroyed no later than June 1, 2014.

Risk and Benefits

Due to the personal context of the questions asked, there may have been some emotional risk associated with this study. These risks, however, were minimal and were disclosed on the respondent consent form (See Appendix D). Each respondent was given the opportunity to opt out of any of the questions. Respondents were allowed to stop the online survey at any time. There were no direct benefits to the respondents in this study. There may be future indirect benefits resulting from dissemination of the information to social workers who work within the family systems of older adults.

Data Analysis

Content analysis was used in order to identify and explore themes in the data. The researcher used color-coding to identify particular words and common themes, with additional notation of more specific themes in the margins. Content analysis, as defined by Berg (2009), is “careful, detailed, systematic examination[s] of a particular body of material in an effort to identify patterns, themes, biases, and meanings” (p. 338). The researcher looked for same or similar feelings regarding being a member of family caring for an older adult. Qualitative research is able to address “the richness and complexity of human behavior one encounters in social services” (Monette, Sullivan, & DeJong, 2011, Preface). The use of qualitative data allowed the researcher to obtain a more personal understanding of the families studied.

To improve reliability, the data was also coded by two of my colleagues using the same method to identify patterns, themes and any specific wording. Several themes correlated with those found by the researcher. None of the themes found by colleagues contrasted with what the researcher found. In all cases the interpretation of the colleagues was either identical or similar in depiction to what was found by the researcher. We first performed an informal approach, and merely read the replies and highlighted words and phrases respondents used often. When observing the words used, we all found that certain words were used repeatedly to describe situations and relationships. These repetitions allowed for basic assumptions to be made.

We then completed a systematic search of the responses using the key words of frustration, time and stress. These descriptors were found to be the main focus of respondents' answers. The codes were at first broad and open, and then reduced until specific themes emerged. They included positive and ambivalent as well as stressful and negative statements.

Findings

This study explored the multigenerational family as a single unit through the voice of family members who have a caregiver that is caring for an older adult and the effects of such care. Respondents were willing to share intimate thoughts and feelings on being part of a family with an older adult needing care. This section of the paper begins with a description of the respondents who completed the survey, followed by the four primary themes that emerged from the key questions, and the respondents' responses. It also looks at interventions and supports that were identified by those responding.

The respondent replies to the six core open ended questions were similar in many ways, and several questions had responses that paralleled with the others. After a careful analysis, four main themes were identified. These include a description of the respondents' lives since care began, impact on the family, and impact on personal relationship with caregiver and supports identified.

Description of Life Since Care Began

When asked what has life been like for them since the older adult has needed care, nearly every respondent included an adverse statement using a version of the word stress, frustrate or difficult. Several stated life was "very or increasingly difficult." Three respondents referred to time constraints by "placed limitations on our time," "lots of juggling of priorities," "busier," "at times overwhelming." Others using similar word or phrases described life as "frustrating and stressful," "somewhat frustrating," "more stressful," "taxing," "emotionally draining" and "exhausting." One adult child stated "My life hasn't changed, but I feel bad for my mom, she is frustrated, puts a lot of time

into it and does not feel appreciated. I am her sounding board,” while a spouse specified “increasing difficult and stressful.”

Impact on the Family

Ten of the sixteen survey respondents were able to identify positive benefits associated with being a part of the family. One felt special to be able to be a part of the family providing care, while another stated due to the increased need, they saw her more often “like going to church, breakfast out and visiting.” Another respondent specified that there was a positive effect to my mom needing care “as now am talking with my dad more often.” Similarly another responded that they were “now closer than ever” [with the older adult]; “We bond”. Another daughter stated she and her mom were “so much closer” which she followed with; “I know my mom so much better, we share things that we might never have, if my dad had not started having so many health problems.” Other relevant positive comments included, “The kids enjoy the visits,” “We are closer,” “We talk daily and that talking together has increased.”

Fear of the unknown including unexpected changes was noted by several of the respondents. These fears included; illness and decreasing abilities/strengths of both the older adult and the caregiver. One respondent noted that my “mother had not volunteered for the grandmother to be ill and she [mother] was “thrown’ into it.” Another wrote about how they worried about “mom’s decreasing health since she began caring for dad” and now “tries to make visits [they live in a different state] more frequently.” Additionally another respondent, when speaking about the grandmother stated that “there is a lot of unpredictability, as various problems arise.” A caregiver’s spouse stated it is “frustrating, [as] there is always something unforeseen needing attention.” Equally significant another

stated “Anytime there is an older adult who needs care and support, there is a lot of unpredictability as various problems arise.” Respondents used the descriptors “stressful,” “worry,” and “difficult” in virtually every facet of this study. One respondent acknowledged “The family vents on each other often,” while another replied “Everyone is stressed out.”

Seventy-five percent of the responses regarding holidays and family times also included adverse effects on the family. These responses comprised statements such as “totally altered holidays” and “we now plan everything around mom’s [older adults] schedule.” Holiday gatherings with distant family members have become less involved due to the care and planning needed, according to respondents, and caregivers are sometimes unable to participate due needing to care for older adult. Respondents’ replied included “planning is more difficult,” there is “less family time,” “it makes family situations very complex,” and “dinners are loud due to everyone yelling so the older adult needing the care can hear.” Also noted was how the caregiver’s tasks can affect family dinners, “Dinner is cut short due to decreased amount of energy in the older adult needing care and less energy of the caregiver.”

Personal Relationship with the Caregiver

For the majority of the respondents, the personal relationships with the caregiver invoked a distinctly negative response. “Stress,” “stressful,” and “frustration,” used to describe life since care began, were once again the primary descriptors used by respondents to describe their personal relationship with the caregiver. These descriptive responses were followed up by respondents with additional assertions of “less tolerant,” “horrible,” “less time,” “resentment,” and “misunderstanding.” One family member

stated “I’ve become someone she [the caregiver] can vent her frustrations to about her responsibilities and experiences caring for my grandmother.” Conversely another stated “I watched caregiving by my mother to her father emotionally drain her, as well as take a physical toll on her [caregiver]. Time is needed and patience.” A different respondent exclaimed “It has added stress and if we disagree on a decision, it can carry over into our [spouse and caregiver] relationship.” Equally another shared feelings of being overlooked, “I feel so alone when I need some help because our older family member takes precedence. Sounds selfish, but it is true.”

Conversely, several responses were notably positive. Three respondents stated succinctly “we are closer,” while another respondent expanded on this idea “we are closer, but I wonder if it is due to the caregiving, or [the fact] that I am older and more mature.” Also noted, “We are seeing each other more and we talk more.” Similarly another adult child declared “I am hearing from my dad more. His role is stressful... he needs reassurance.”

With 80% of the respondents replying to this question, only a few voiced ambivalence or conflict in the relationship. “Hearing from my dad more due to his role being stressful” was voiced as well as “we both bond together and get frustrated with each other.” Likewise was “Made me feel the need to help out more seeing the stress it causes the caregiver.” This respondent summoned up the experience as, “It is worth it. Families are challenging, but I would be lost without them. It is worth all the adjustments and sacrifices.”

Supports

The survey question “what supports (e.g. social, financial, other), if any, would contribute to the well-being of your family” summoned a diverse group of replies. In response to this question, which focused on the family, several respondents spoke about support that comforts the caregiver, while others referred to the needs of the older adult.

Although the specific words used to define needed supports were varied, emotional support for the family clearly was the benefit that the majority identified as deficient. Examples of respondent declarations of this required need include “emotional support for everybody else in the family,” “support from other extended family members,” and “extended family members taking turns providing care, rather than leaving it up to my mom would be a big help.”

Support for conflict resolution was also noted by one respondent who detailed the need in their response as;

The discord between him [caregiver] and his siblings makes it the most difficult, they [family siblings] guilt each other about different things. It takes three times as long for them to make a decision...they tend to argue more than they worry about their mother's condition.

Several respondents noted that knowing that the older adult was receiving good care while residing in a senior facility was a benefit to the family. One of member proclaimed that “currently, [our] elder is in a good facility and is receiving excellent care, which is the best support for our family.” Another respondent explained “the staff at the facility is very helpful when we have concerns regarding my mom's physical and mental health.”

The specific need for financial support was noted by 25% of those responding. These responses included simply “funding for a nursing home” and “financial.” However, one respondent was more explicit by saying “Financial support would be great! Mom and Dad both worry about how to pay for an assisted living facility when it's time that Dad get [receives] a higher level of care than my Mom can give.” Another stated “I work with older adults myself, and I forget how little people in the ‘real world’ know about navigating the [financial] system, and understanding what [economic assistance] is available to people.”

Other support needs reported included assistance in “Feeling more comfortable that her [older adult’s] non family caregivers were meeting all of her [older adult’s] needs” as well as “continued social support for my Mom and Dad [is] crucial.” Another respondent noted that, “Any help is good; however, it is difficult to ask for help.” Resources in general, concerning caring for an older person were also identified as a need, including social and nutritional support as well as time to make up for the things the caregiver used to do. Only one person who answered this question stated no support is needed.

Discussion

The purpose of this research was to explore the family as a unit, in particular the effects on the multigenerational family when at least one person is giving care to an adult over the age of 65. These findings are consistent with the literature assertions that members of a family are a unit and what affects one [member] also affects the whole family. Bowen (1966) found that the parts (persons) in a family are interrelated beings exhibiting behaviors through the interactions among each other with each one dependent on the other. Moreover, as identified by Rooney, Rooney, and Strom-Gottfried (2013) these interactions within a family create the whole.

Family Life

Respondents in this study validated the idea that since care for an older adult began, family life was found to be very stressful and frustrating. As one member stated, “There is always something unforeseen needing attention.” Life is frustrating, as according to another respondent having a family member caregiver has “placed some limitations on our lifestyle.” It is also stressful as there is lots of “juggling of priorities.”

This study found that having a family member caring for an older adult member does affect the whole family. All members are an important part of the family unit. Some respondents felt there are times that their needs are overlooked. This can be heard in one respondent’s voice stating that they often were “feeling alone as the older family member always takes precedence ... Sounds selfish, but it is true.” Therefore, as the prior research of Zhang, Kao, and Hannum (2007) identified, there is a growing need to include the family when determining quality care for our aging population.

Families often live in fear of the unknown, unable to plan even the simplest of activities. As one voice stated, “Life is a like a roller coaster, one acute illness after another, and never knowing what will happen next, it’s a very difficult roller coaster.” Likewise another accentuated that “even simple illness like a cold can derail appointments and schedules.” Family members learned to adjust their own schedules to assist the caregiver during times of acute illness, of worry, and as one respondent described, “The ever impending crisis.”

Communication between members can also be difficult. Distance and busy lives often add to this frustration. Respondents reported venting on each other, arguing over care for the older adult and whose turn it was to do something. Sanders (2003) declared that by “strengthening the quality of family interaction [we are able to] reduce the stress”. Encouraging communication is a key aspect of enhancing the lives of these families with caregivers of an older adult. This correlates to research that emphasized using the emotional connection piece found in the Family Systems Theory, the family-centered, strength-based approach is able to use the positive aspects of the members to reinforce communication and interaction within the family unit (Bowen, 1995; Sanders, 2003).

Relationship with Caregiver

The families’ relationships with the caregiver of the older adult had an impact on family dynamics, according to many of the respondents. If the caregiver was stressed and overwhelmed, this feeling also seemed to drift to the other members. This is consistent with Riley and Bowen (2005), who found that we must recognize that there is relationship between increased stress for caregiver and its effect on the children of the caregiver.

Respondents also felt left out or overburdened themselves as they took on additional responsibilities that were previously performed by the caregiver. The National Stroke Foundation (2014) has determined that “Caring for stroke survivors at home can cause high levels of emotional, mental and physical stress.” Furthermore, The National Stroke Foundation (2014) asserted that “in addition to distress, disruption of employment and family life makes caregiving very challenging” (para. 1). The responses generated in this study are similar to those found by The National Stroke Foundation, therefore suggesting that caring for an older adult is no different. The caregiver duties do affect the family.

Conversely some respondents reported that their families were able to step up and fall back on the strength of the family unit. For example, “there was a positive effect to my mom needing care, as now am talking with my dad more.” Others stated they are closer as they felt the need to help out more and are spending more time together. Equally, some felt the stressful situation assisted in bonding the family together. Sander (2003) when referring to caregiving, asserted that it is important “for the quality of your family relationships that you find that time.” It was almost as if they now had a reason or a purpose to get together. Possibly in these busy times, this was a needed reason for some families to support one another.

Relationship with Older Adult

While this study did not focus on the relationship with the older adult, several insights did come forth. Family connection became important as the older adult’s needs rose. Some families found that having an older adult needing care had encouraged them to say in contact more often. One respondent stated they brought their children, the older

adult's great grandchildren, to visit more often, which often served a second benefit of relieving the caregiver for a short time. Holidays, family dinners and special occasions were reportedly adjusted in time, place and length to make allowance for and encourage the inclusion the older adult.

Support and Needs

Financial need for the older adult, the caregiver and the family as a whole was noted as one of the largest needs. This was consistent with the findings of Cox and Soldo (2013) and Genworth's Cost of Care Survey (2012) that financial needs are of paramount concern to many older people and their caregivers/families.

Working through the system of local, state, and federal benefits and programs is sometimes discouraging in itself. This need was expressed by one family member as being very complex. Her voice can be heard in; "I work with older adults myself and I forget how little people in the 'real world' know about navigation the system and understanding what is available to them." Research has also notated this need and suggested we as social workers can assist. Barnes, Given, and Given, (1995) identified that "sorting out the kinds of assistance," for an older adult needs is often the chief undertaking for social workers working with caregivers (p. 376). The professional experience of the author on this study has also found this locating and "sorting of assistance" to be a top priority for the majority of her clients.

The need for emotional support was noted as respondents reported numerous times how stressed and worried everyone was. One respondent particularly stated how the venting on each other makes communication difficult at times. Respondents wondered if possibly in these busy times, this was a necessary reason for some families to

support one another. As one respondent suggested, they needed the family cooperation and support now more than ever.

Implications for Social Work Practice

This study suggests that as social workers, we have an obligation to include the family when working with the older adult. This includes therapeutic practice, as well as in the development of specific treatment options. By utilizing interventions rooted in evidenced based family systems theory, we will be able to offer better service as if we look at the family as one client (McHale & Sullivan, 2007).

Bookman and Kimbrel (2011) found that, although, our aging population in the United States is increasing, the majority of people are uninformed about most things when it comes to the care of the older adult. This adds a huge amount of stress and frustration to the family. Therefore, as social workers we must become better informed if we are to meet these increasing family needs, in both clinical practice and supportive services which include financial, housing, and nutrition.

In keeping with the systems theory, this study suggests that services to older adults should include a family emphasis, which correlates with Hannum et al. (2007) in which they proposed that, while the care should be “patient centered,” it should also be “family focused.” By focusing on the family relationships, we can empower the families to weather the storms and support each other in both these day to day needs and the ever imminent emergency and to work together during this sometimes frustrating time. The suggestions of the respondents; specifically financial support, emotional support, social support and nutritional support should be further explored for implementation into social work practice, to assist in coping with the newly changed family system.

Implications for Social Work Policy

Financial constraints place limitations on families with an older adult needing care. Policies to assist these families are needed, to help alleviate some of this additional family strain. With funding for social services decreasing, and basic need increasing, Medicare funding and resources must to be reevaluated to include the additional services older adults need. Advocacy is needed at the local, state and national level to ensure monies are made available for programs to assist to the older adult and the caregiving family with basic daily care expenditures.

In addition to our lower socioeconomic families, social work policy should include advocating on behalf of additional funding for nursing homes, assisted living facilities and home care needs to also address the basic needs of the middle class.

Implications for Social Work Research

Further research is needed to study the interaction between family members and the caregiver, as well as the older adult and the family unit. The relationship between older adult and caregiver, as well as the children's relationship with the older adult, may offer some further insight into the family dynamic.

Developing a study that uses precise questions with a couple of follow up questions would assist in achieving a more exact resulting assessment than what this study could provide. Future research using a larger sample and more in-depth questions will better enhance our understanding of the needs of families with a caregiver caring for an older adult. Focus group research will allow the researcher to follow up with added questions to assist in defining the family responses. Other suggestions include using a

predetermined set of questions and interviewing several members of an individual family at the same time to both hear spoken words and observe behaviors as they interact.

Strengths and Limitations of Research Design

The qualitative research design allowed collection of rich data about human needs, behavior patterns, and emotions. This design allowed the survey respondents to describe these characteristics and offer personal opinions which cannot be reduced to simple numbers.

The limitations that affected the scope of this study's findings included a small sample size and lack of ability to follow up with the respondents to the online survey. For example, some of the respondents did not answer all the questions. I was unable to verify if they had no response or they did not understand the question. A survey also limits clarification of responses.

Time constraints were also a limitation as due to school parameters, the short time frame allowed for set up, response and analysis was much too short to do a comprehensive study.

This research did not address racial or social economic issues that may affect felt levels of stress or social supports. It is unknown how these areas would increase or decrease the reported felt stress or social support levels. Further research is required.

Conclusion

This study did find that there is a need to address the concerns regarding working with families offering care to an older adult. The results of this study are consistent with prior research that indicates that when working with older adults needing a caregiver, it is in the best interest of the older adult to include the family (Hannum et al., 2007 & Zhang, Kao, and Hannum, 2007). As the older population increases in size, their need for basic care also grows and more families will become affected. There is an increasing need for these families to have support and resources available. It is important that as social workers we gain the knowledge and preparation to meet this need. Social workers who work with older adults, their caregivers and families can integrate information regarding funding, resources and emotional support into their practice to actively affect the change and better serve families that include one or more caregivers caring for an older adult. This can be done by observing and empowering the family as a single unit.

References

- Alzheimer's Association. (2011). Alzheimer's disease facts and figures. *Alzheimer's and Dementia*, 7 (2), 208-244. doi:10.1016/j.jalz.2011.02.004
- Archbold P.G.& Stewart B.J.(2005). Development of the family care inventory: 20 years of nursing research. *Journal of Japan Academy of Nursing Science*, 25,104–112.
- Baillie, V., Norbeck, J. S., & Barnes, L. E. (1988). Stress, social support, and psychological distress of family caregivers of the elderly. *Nursing Research*, 37 (4), 217-222.
- Barnes, C.L., Given, B., & Given, C. W. (1995). Parent caregivers: A comparison of employed and unemployed daughters. *Social Work*, 30(3), 375-381.
- Bavelas, J.B., Segal, L. (1982). Family systems theory: Background and implications. *Journal of Communication*, 32(3), 99–107. DOI: 10.1111/j.1460-2466.1982.tb02503.x.
- Bianchi, S. M. & Casper, L.M. (2000). American families. *Population Bulletin*, 55(4), 1-48. Retrieved from: <http://www.prb.org/Publications/Reports /2000/AmericanFamilies PDF458KB.aspx>
- Boorman, A. & Kimbrel, D. (2011). Families and elder care in the 21st century. *Work and Family*,21(2), 117-140
- Bowen, M. (1966). The use of family theory in clinical practice. *Comprehensive Psychiatry*, 7(5), 307-462. Retrieved from: www.sciencedirect.com /science /journal /0010440X/7/5
- Bowen, M. (1995). Clinical view of the family. *Family Systems*, 2(2), 153-156

- Bowen Theory (ND) Family systems theory. *Bowen Center for the Study of the Family*. Retrieved <http://www.thebowencenter.org/pages/theory.html>
- Bradley, L. J., Whiting, P. P., Hendricks, B., & Wheat, L. S. (2010). Ethical imperatives for intervention with elder families. *The Family Journal*, 18(2), 215-221. DOI: 10.1177/1066480710364507
- Canter, D. (1983). The purposive evaluation of places, A facet approach. *Environment and Behavior*, 15(6), 659-698. doi: 10.1177/0013916583156001
- Cattan, M., White, M., Bond, J., & Learmouth, A. (2005). Preventing social isolation and loneliness among older people: A systematic review of health promotion interventions. *Ageing and Society*, 25(1), 41-67.
- Connidis, I. R. & McMullin, J. L. (2002). Sociological ambivalence and family ties: A critical perspective. *Journal of Marriage and Family*, 64(3), 558-567.
- Connidis, I. R. (2010). *Family ties and aging*. (2nd ed.). Thousand Oaks, CA: SAGE Publications
- Coughlin, J. (2010). Estimating the impact of caregiving and employment on well-being. *Outcomes & Insights in Health Management*, 2(1),1-7.
- Cox, D., & Soldo, B. (2013). Motives for care that adult children provide to parents: Evidence from "point blank" survey questions. *Journal of Comparative Family Studies*, 44(4), 491-524.
- Fingerman, K.L., Hay , E. L., Kamp Dush, C.M., Cichy, K. & Hosterman, S. (2007). Parents' and offsprings' perceptions of change and continuity when parents experience the transition to old age. *Advances in Life Course Research*, 12, 207-306. Doi: 10.1016/S1040-2608(07)12010-4

- Genworth. (2012). Genworth 2012 cost of care survey. *Genworth Financial and National Elder Care Referral System*. Richmond, Virginia Retrieved from https://www.genworth.com/dam/Americas/US/PDFs/Consumer/corporate/Key_Findings1.pdf
- Gordon, J.R., Pruchno, R.A., Wilson-Genderson, M., Murphy, W. M. & Rose, M. (2012) Balancing caregiving and work: Role conflict and role strain dynamics. *Journal of Family Issues*, 33(5), 662-689.
- Greene, R.R. (2008). Family systems. *Social work with the aged and their families* (3rd, ed.), (14-15), New Brunswick, NJ: Transaction Publishers.
- Hagestad, G. O. (2003). Interdependent lives and relationships in changing times: A life-course view of families and aging. In R. A. Settersten Jr. (Ed.), *Invitation to the life course: Toward new understandings of later life*, (135-159), Amityville, NY: Baywood.
- Halm, M. A. (1990). Effects of support groups on anxiety of family members during critical illness. *Heart & Lung: The Journal of Critical Care*, 19(1), 62-71.
- Hartman, A. (1995). Diagrammatic assessment of family relationships. *Families in Society*, 76, 111-122.
- Igarashi, H., Hooker, K., Coehlo, D. P., & Manoogian, M.M. (2013). "My nest is full:" Intergenerational relationships at midlife. *Journal of Aging Studies*, (27)2, 102-112.
- International Monetary Fund. (2009). *Annual report of the executive board for the financial year ended April 30, 2009*. Washington, DC: Report team

- Johnson, C. L., & Catalano, D. J. (1983). A longitudinal study of family supports to impaired elderly. *The Gerontologist*, 23(6), 612-618.
- Johnson, E. S. & Spence, D. L. (1982) Adult children and their aging parents: An intervention program. *Family Relations*, 31(1), 115-122.
- Jones, S.L., & Dimond M. (1982). Family theory and family therapy models: Comparative review with implications for nursing practice. *Journal of Psychosocial Nursing and Mental Health Services*, 20(10), 12-19.
- Kerr, M. E. (2008). *Family evaluation: An approach based on Bowen theory*
New York, NY: W. W. Norton & Company.
- Krueger, R. A. & Casey, M. A. (2009). *Focus groups: A practical guide for applied research*. (4th ed). Thousand Oaks, CA: SAGE Publications.
- Lenz, E. R., & Perkins, S. (2000). Coronary artery bypass graft surgery patients and their family member caregivers: Outcomes of a family-focused staged psychoeducational intervention. *Applied Nursing Research*, 13(3), 142-150.
- Li, H. (2005). Hospitalized elders and family caregivers: a typology of family worry. *Journal of Clinical Nursing*, 14, 3-8.
- McHale, J. P., & Sullivan, M. (2007). Family systems. In A. Gross (Ed.), *Handbook of clinical psychology*, (192-226) Hoboken, NJ: John Wiley & Sons.
- Madrigal, D. & McClain, B. (2012). Strengths and weaknesses of quantitative and qualitative research. *UXmatters*. Retrieved from: <http://www.uxmatters.com/mt/archives/2012/09/strengths-and-weaknesses-of-quantitative-and-qualitative-research.php>

- National Association of Social Workers. (2008). *Code of ethics of the National Association of Social Workers*. Washington, DC: NASW Press.
- National Stroke Association. (2014). *Caregivers and families*. Retrieved from <http://www.stroke.org/site/PageServer?pagename=care>
- Ottmann, G., Dickson, J., & Wright, P. (2006). Social connectedness and health: A lit review, *Cornell University IRL School*. Retrieved from <http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1474&context=gladnetcollect/471>
- Pruchno, R.A., Burant, C.J. & Peters, N.D. (1997). Coping strategies of people living in multigenerational household effects on well-being. *Psychology and Aging*, 12 (1), 115-124
- Qiu, W. Q., Dean, M., Liu, T., George, L., Gann, M., Cohen, J., & Bruce, M.L. (2010). Physical and mental health of homebound older adults: An overlooked population. *Journal of the American Geriatrics Society*, 58(12), 2423–2428.
- Rice, D.P., & Fineman, N. (2004). Economic implications of increased longevity in the United States. *Annual Review of Public Health*, 25, 457-473.
- Richmond, M. (1922). What is social case work? An introductory description. Russell Sage Foundation. Retrieved from: <https://archive.org/stream/whatisocialcase00mary#page/n3/mode/2up>
- Riley, L. D. & Bowen, C. P. (2005). The sandwich generation: Challenges and coping strategies of multigenerational families. *The Family Journal*, 13(1), 52-58.

- Robison, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. *The Journals of Gerontology. Series B: Psychological Sciences and Social Sciences*, 64(6), 788-798.
- Rollins, J. (2008). The graying of the baby boomers. *Counseling Today*, 51(4), 32-37.
- Rooney, R. H., Rooney, G. D., & Strom-Gottfried, K. (2013). *Direct Social Work Practice: Theory and Skills*. (9th ed.) Boston, PA: Person Education Inc.
- Sands, L.P., Ferreira, P., Stewart, A.L., Brod, M. & Yaffe, K.(2004). What explains differences between dementia patient' and their caregiver ratings of patients quality of life? *American Journal of Geriatric Psychiatry*, 12(3), 272-280.
- Sanders, G. (2003). Family relations and caregiving. The journey through caregiving. The North Dakota Caregiver Project. University of North Dakota. Retrieved from <http://www.ndsu.edu/ndsu/aging/caregiver/pdf/family/module.pdf>
- Satir, V. (1983). *Conjoint family therapy*. (3rd ed.) Palo Alto, CA: Science and Behavior Books.
- School of Nursing, Oregon Health Sciences University (1994). *Family caregiving inventory*, Portland, OR: Archbold, P.G. & Stewart, B.J.
- Settersten, R. & Ray, B.E. (2010) *Not quite adults*. New York, NY: Bantam Books.
- Stewart, S.T., Cutler, D. M., & Rosen, A. B. (2013).US trends in quality-adjusted life expectancy from 1987 to 2008: Combining national surveys to more broadly track the health of the nation. *American Journal of Public Health*. 103(11).DOI:10.2105/AJPH.2013.301250

- System. (2013). In *Merriam-Webster*. Merriam-Webster.com. Retrieved from:
<http://www.merriam-webster.com/dictionary/system>
- The Pew Foundation. (2012). *The reversal of the college marriage gap*. Washington, DC;
 Richard Fry
- United States Government, Department of Health & Human Services Administration on
 Aging (2010). *Profile of Older Americans* Retrieved from
[http://www.aoa.gov/AoARoot/Aging Statistics /Profile/index.aspx](http://www.aoa.gov/AoARoot/Aging%20Statistics/Profile/index.aspx)
- University of Massachusetts Medical School (2013). Americans living longer, more
 healthy lives. *ScienceDaily*. Retrieved from [http://www.sciencedaily.com- /
 releases /2013 /09/130912203321.ht](http://www.sciencedaily.com/releases/2013/09/130912203321.htm)
- Victor, C. Scrambler, S. Bond, J. and Bowling, A. (2000). Being alone in later life:
 Loneliness, social isolation and living alone. *Reviews in Clinical Gerontology, 10*,
 407-417.
- Whiting, P. & James, E. (2005). Bearing witness to the story: Responses to shadow grief
 in diverse family context. *Journal of Healing Ministry, 12*, 31-34.
- Wivell, J., & Mara, D. (2010). 'Without my faith I would break into pieces.' Supporting
 elder family members: Implications for social work policy and practice. *Aotearoa
 New Zealand Social Work, 22(2)*, 13.
- Zhang, Y., Kao, G., and Hannum, E. 2007. "Do mothers in rural China practice gender
 equality in educational aspirations for their children?" *Comparative Education
 Review, 51(2)*, 131-157.

Ziemba (2002) Family health & caring for elderly parents. *Michigan Family*

Review, 7(1), 35-52 Retrieved from: <http://hdl.handle.net/2027/spo.4919087>.

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Appendix A

Recruitment Flyer

Volunteers Needed for Research Study

Participants needed for a research study:

“EFFECTS ON THE FAMILY WHEN ONE MEMBER IS A CAREGIVER TO AN AGING PERSON”

Description of Project:

Graduate Social Work Student researching the effects on the family when one member is a caregiver to a person over 65 years of age. Your participation in a focus group is requested. The Focus group will take about 90 minutes.

To participate:

You must be over 18 and under 65 years old, not considered to be a vulnerable adult and a member of a family with at least one caregiver of an aging person over 65. You must not be the primary caregiver.

Participants will be served coffee, bottle water and cookies.

To learn more, or to sign up, contact the investigator of the study.

Deborah Mason, LSW 651-373-0415 or maso2469@ust.edu.

If you are unable to participate in the focus group, yet would like to participate; please contact the researcher for the link to an online survey.

This research is conducted under the direction of Abel Knochel, PHD, LGSW, Social Work Department, and has been reviewed and approved by the St Catherine University Institutional Review Board.

Appendix B

Email to AEA Scholars Program

For my final project in my journey toward my graduate degree in clinical social work at the University of St Thomas/St Catherine, I am to do a research project. My interest is working with older adults and their families.

The purpose of my research is to explore the family as a unit, in particular the effects on the multigenerational family when at least one person is giving care to an adult over the age of 65. This research will explore the needs of the multigenerational contemporary family caring for an older adult and identify ways social workers can support the entire family as a caregiving unit.

I am looking for family members of a caregiver living in the Twin Cities and surrounding Metro area to participate in a 90 focus group on a Saturday afternoon in February. If you are unable to participate in the focus group but would like to offer input I have also posted a short anonymous survey. You may email me at maso2469@stthomas.edu to participate or for more information. Please put the word research in the topic so I know it is not spam. Thank you

Appendix C

Posting on Social Workers Allied for Problem Solving (SWAPS)

Greetings,

My name is Deborah Mason and I am a Social Worker attending the University of St Thomas/St Catherine working toward my graduate degree in clinical social work. For my final project I am to do a research project. My interest is working with older adults and their families.

The purpose of my research is to explore the family as a unit, in particular the effects on the multigenerational family when at least one person is giving care to an adult over the age of 65. This research will explore the needs of the multigenerational contemporary family caring for an older adult and identify ways social workers can support the entire family as a caregiving unit.

The Alton and the Wellington recognize the importance of family involvement when caring for an older adult and have been kind enough to assist me in this project. I am looking for family members of a caregiver to participate in a 90 focus group on a Saturday afternoon in February. If you are unable to participate in the focus group but would like to offer input I will be posting a short anonymous survey. You may email me at maso2469@stthomas.edu to participate or for more information. Please put the word **research** in the topic so I know it is not spam.

Please see the attached flyer for further information

Thank you,

Deborah Mason, LSW

University of St Thomas/ St Catherine

Appendix D

Protection of Respondents

ONLINE SURVEY INFORMATION AND CONSENT FORM

Introduction:

You are invited to participate in a research study investigating the effects on the family when one member is a caregiver to an aging person. This study is being conducted by Deborah Mason, LSW, a graduate student at St. Catherine University under the supervision of Abel Knochel, PHD, LGSW, a faculty member in the Department of Social Work. You were selected as a possible participant in this research because (1) you are 18 years of age or older and not considered to be a vulnerable adult and (2) are a member of a family with at least one caregiver of an aging person over the age of 65. Please read this form and email mason2469@stthomas.edu with questions before you agree to be in the study.

Background Information:

The purpose of this study is to determine the effect[s] on the family when one member is a caregiver to an aging person. The goals for this study are to gain perspective on family dynamics as well as, to discover and promote best practice for Social work when one member is a caregiver an aging person. For the purpose of this study an aging person or an elderly person will be someone who is 65 years of age or older.

Procedures:

If you decide to participate, you will be asked to electronically sign an informed consent, confirming, (1) you are 18 years of age or older and not considered to be a vulnerable adult and (2) are a member of a family with at least one caregiver of an aging person over the age of 65, that you agree to participate in the online survey and have your answers recorded via Qualtrics. This survey will take approximately 20 minutes and must be completed in one session.

Risks and Benefits of being in the study:

There is minimal likelihood of risk for this study. However, due to the personal context of the questions, there is a possibility of some strong or vulnerable emotions. Respondents will be given the opportunity to opt out of any questions. Respondents will have the freedom to decline to participate at any point in the process and allowed stop the online survey at any time.

There are no direct benefits to you or any respondent for participating in this research study.

Confidentiality:

Any information obtained in connection with this research study that can be identified with you will be will de-identified by not disclosing any email or IP addresses. Your answers will be kept confidential. In any written reports or publications, no one will be

identified or identifiable and only group data will be presented. Respondents will be coded with numbers rather than names to protect their confidentiality and family privacy. Downloaded data will be saved in a word document on the researcher's, password protected desktop computer

I will keep the research results in a locked file cabinet in my home, only I and my advisor will have access to the records while I work on this project. I will finish analyzing the data by May 19th, 2014. I will then destroy all original reports and identifying information that can be linked back to you. I will destroy all data including the audio tape no later than June 1, 2014.

Voluntary nature of the study:

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your future relations with Alton Memory Care, Golden Living Center, The Wellington Senior Living University of St. Thomas, or St. Catherine University in any way. If you decide to participate, you are free to stop the survey at any time without affecting these relationships.

Contacts and questions:

If you have any questions, please feel free to contact me, Deborah Mason, LSW at 651-373-0415 or maso2469@ust.edu. You may ask questions now, or if you have any additional questions later, the faculty advisor, Abel Knochel, PHD, LGSW, can be reached at 612-876-2125, and will be happy to answer them. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher, you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at 651- 690-7739.

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

Statement of Consent:

You are making a decision whether or not to participate. Your clicking the yes button indicates that you have read this information and your questions have been answered. Even after electronically signing this form, please know that you may withdraw from the study at any time by exiting the survey

By clicking yes on:

“I have read and understand this statement and consent to participate in the study” will act as your electronic signature.

Appendix E

Email Sent To Those Who Requested To Take Survey

Thank you for wanting to assist with my graduate research project “Effects on the Family When One Member Is a Caregiver to an Older Adult: A Social Work Perspective.”

I appreciate your wanting to help by taking the survey. You can find it at this link

http://stthomasbusiness.az1.qualtrics.com/SE/?SID=SV_8zQW55112Yceexv

Thank you without your participation I could not complete the project.

Deborah Mason, LSW

Appendix F

Survey Qualifications and Questions

Effect on The Family When One Member is a Caregiver to an Aging Person

Qualifications:

I am off legal age, minimum of 18 years old and not over the age of 65?

Yes

No

I am not considered to be a vulnerable adult as of the date I am filling out this survey?

Yes

No

There is one or more persons in my family that provide care for a person over 65?

Yes

No

If the answer is not yes to all questions, the respondent will be sent a notice of appreciation but disqualification from the survey. (See appendix F).

Survey Questions:

The survey questions are as follow:

1. Mark the correct answer for the question: Where does your elderly person live?
 - A. Family Home
 - B. Assisted Living
 - C. Nursing Home
 - D. Other (please describe)
2. Who gives the care to the older adult?
 - A. My Spouse
 - B. My Mother
 - C. My Father
 - D. My Sibling
 - a. Sister
 - b. Brother
 - E. Other - Please list
3. How long has this person been the older adult's caregiver in your family??
 - A. Less than one year
 - B. One -Two years
 - C. Three to Five years
 - D. Over 5 years
4. Are there children under 18 living in the home?
 - Yes
 - No

5. What has life been like for you since the older adult over 65 has needed this care?
6. What impact (if any) has there been on the family as a whole living with a caregiver of an elderly person?
7. Please explain how the caregiving experience affects family time [if at all]?
e.g. [dinners, holidays, financial, other]
8. How, if at all, has your personal relationship with the caregiver in your family been affected by their role of caregiving?
9. What supports, if any would contribute to the well-being of your family and allow your family to provide care to this older adult?
10. What else, if anything, would you like to share regarding being part of a family with an older adult needing a caregiver? (If nothing then leave blank).

When finished with the survey, the respondent will be asked to submit it

Appendix G

Survey Disqualification Notice

Thank you for wanting to participate in my research project. Unfortunately, you do not meet the qualifications to continue.

If you have further questions please email maso2469@stthomas.edu

Appendix H

Survey Completion Notice

Thank you for participating in my research project. Without your participation this research product would not be possible.

If you would like a copy of the results of my project please email maso2469@stthomas.edu with the words 'Request Project Results' in the subject line.

Appendix I

Coder Confidentiality Agreement

I, _____ agree to maintain full confidentiality in regards to any and all documentations received from Deborah Mason, LSW related to her research study on the researcher study originally titled Effect on the Family When One Member Is a Caregiver to an Aging Person. Retitled as: The Family's Voice: Caregiving for an Older Adult

Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the coding of any associated documents.
4. To return all study-related materials to Deborah Mason, LSW in a complete and timely manner.

I am aware that I can be held legally responsible for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the audiotapes and/or files to which I will have access.

Coder's name (printed): _____

Coder's signature: _____

Date: March 13, 2014

Appendix J

Research Permission One

Research permission

Mon, Nov 25, 2013 at 1:24 PM

To: "Mason, Deborah J." <maso2469@stthomas.edu>

To Whom it May Concern at St. Catherine University:

The Wellington is agreeable to helping Deborah Mason in the collection of research participants for her MSW project.

We will plan to send out an email to our resident's families with a link to Deb's online survey. This email will also include Deb's invitation to participate in an optional focus group.

Appendix K
Research Permission Two

From:

To: St. Catherine University, University of St Thomas and IRB:

MSW project titled: Effects on the Family When One Member Is a
Caregiver to an Aging Person: A Social Work Perspective

I, xxxxxx, Social Services Director at Golden Living Center-St. Louis
Park along with my social work team are agreeable to assisting Deborah
Mason, BSW, LSW with in the collection of research participants for her
MSW social work research project.

My social work team and I have planned a meeting on December 20th,
2013 to allow Deb to explain her project in detail and pass out the
flyers for our residents' families. We will also post her flyers on the
community bulletin board. We will plan to send out an email to our
residents' families with a link to contact Deb regarding the online
survey. This email will also include Deb's invitation to participate in
an optional focus group.

Sincerely,