

CAREGIVER STRESS: FIRST PERSON ACCOUNTS OF THE PERCEPTION AND
UTILIZATION OF SUPPORT SERVICES

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ABSTRACT

The majority of care for older adults is provided in the home. Many studies show that the daily demands placed on informal care providers produce high degrees of strain and stress. In an effort to reduce the over-arching impact care provider burnout can have on the entire family system, a number of community organizations offer resources to informal caregivers in the form of support groups, respite care and skills-training. More research is needed regarding the extent to which informal caregivers utilize these services. The objective of this paper is to assimilate more information about how care providers learn about available resources, which ones are used, and how the care providers' needs are being supported. Key themes from these data could provide service providers with insights regarding: the effectiveness of their marketing strategies; ways current services could better serve a larger, more diverse population; and potential new services.

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INTRODUCTION

With 12% of the U.S. population over the age of 65, the need and demand for informal care providers is rising (Washington, Meadows, Elliot, & Koopman, 2011). AARP (2015) reports there are about 40 million family (informal) caregivers in the United States providing approximately 37 billion hours of care to adults with limitations in daily activities. Caregiving duties can include assisting the care recipient with household or daily living tasks (e.g., cooking, cleaning, driving, bathing or dressing), managing personal finances, or providing transportation. A study by AARP (2015) reports that the majority of care provided to older adults is given by family and friends (informal) and not by a paid professional (formal). However, unlike professional caregivers, most informal care providers do not have a high degree of formal skills training or education on how to: provide complex care (i.e. medical/skilled nursing tasks); create a care team to share the load; nor identify support services available within their community (AARP, 2015; Castora-Binkley, Noelker, Ejaz & Rose, 2010). AARP (2015) also reports that the majority of caregiving is provided by female family members who are generally simultaneously providing care to other family members as well as trying to hold down a full or part-time job, placing the primary informal caregiver under a high degree of strain and stress which can lead to burnout, chronic stress, depression and elder abuse.

In response to the numerous reports identifying the health risks associated with being a care provider (AARP, 2015; Castora-Binkley et al., 2010; Washington et al., 2011) the care industry has experienced a boom in resources available through community organizations and business ventures offering assistance to informal caregivers in the form of support groups, respite care for the care recipient, tips for self-care and education and training on how to be a care provider (Pratt, 2016; Won Won, Sizer Fitts, Favaro, Olsen & Phelan, 2008). It is important to

understand whether and how informal caregivers become aware of these services, which ones they utilize, and if the programs sufficiently aid in meeting their needs and mitigate their risk for stress, depression and developing their own set of chronic illnesses. Factors that contribute to the process of service selection are contingent upon the caregiver's cultural values, cohort, education, financial resources and access points to information (newspaper, internet, computer skills, resource centers, and social support systems). The purpose of the present paper was to examine how a small sample of informal caregivers sought and utilized support services. Data were collected from qualitative interviews with three informal care providers between the age of 60 and 70 residing in California, Colorado and Oregon as well as the retrieval of demographic data collected by a Resource Center located in the Denver Metro area.

LITERATURE REVIEW

Family members, partners and friends account for 85% of the primary care provided to older persons with long-term care needs and another 30% of family care providers will retain part-time fee-based assistance through an in-home non-medical or medical service provider (AARP, 2015). These informal (non-professional) care providers are the backbone of long term care services and support.

Overview of Informal Caregivers

This model of direct and contracted care is what determines whether or not an older person can remain at home. According to Castora-Binkley et al. (2010), when caregivers utilize support services the institutionalization of the care recipient is often delayed. Women account for between 60% – 66% of informal care givers while only 34%-40% of men fill this role (AARP, 2015). A study by MetLife (2011), states that the economic value of the informal care provided by women ranges from \$148 billion to \$188 billion annually. There is great social benefit in the multiple roles women fill as primary informal caregivers to spouses, parents, parents-in-law, friends and neighbors. These roles normally include being a hands-on health provider, care manager, friend, companion, surrogate decision-maker and advocate. It is important to note that while 40% of men are informal caregivers, female caregivers may spend as much as 50% more time providing care than male caregivers (AARP, 2015).

While most studies and the content of this paper are focused on the challenges associated with being a care provider, it is important to note that caregiving can also be rewarding. Some women caregivers report that the role of caregiver gives them a greater sense of purpose and they have more autonomy, more personal growth and more self-acceptance when caring for family members or friends (Green, Aranda, Tieman, Fazekas & Currow, 2011).

Stress and Strain

In a cross race/ethnicity study, AARP (2015) found that the average caregiver is a 48 year old woman caring for her 73 year old mother who does not live with her; she is married and employed. The AARP (2015) study also found that most women will not abandon their caregiving responsibilities because of employment. Instead, they cope, to the best of their abilities, with the combined pressures of caring for a loved one, their need for income, reliance on often inadequate public programs and fewer employment-related benefits. Unmarried women caregivers may have even fewer options for balancing work and caregiving. Several studies have found that women who care for an older relative or friend are at higher risk for depression, anxiety or other mental health challenges than women who are non-caregivers; a middle-aged woman caring for an ill spouse is at six times the risk (Jorgenson, Arksey, Parsons & Jacobs, 2009; Sims-Gould, Martin-Matthews & Gignac, 2008). These studies also show that women who stay at home to provide caregiving do so in part to shoulder the financial burden associated with long-term care. A particularly strong factor in determining the mental health impact of providing care is the amount of care per week that a woman provides. A study by Smith, Williamson, Miller and Schultz (2011) found a marked increase in risk among women who provided 36 or more hours per week of care to a spouse. Researchers concluded that there may be a threshold of time involvement beyond which the likelihood of mental health consequences rapidly escalates (Sims-Gould et al., 2008). Depressed caregivers are more likely to engage in behavior that is harmful to the care recipient such as screaming, rough handling, or threatening to place them in a care facility (Smith et al., 2011). Compounding this picture is the fact that physical ailments among care providers are not uncommon.

Smith et al. (2011) found that more than one-third of caregivers provide intense and continuing care to others while suffering from poor physical health themselves. AARP (2015) cites that although nearly 10% of caregivers are 75 years and older, their age alone does not necessarily place them at higher risk for emotional, physical or financial stress and strain than younger caregivers; however, they are more likely to be caring for a spouse and living on a fixed income which can have a higher impact on their ability to pay for assistance in their caregiving responsibilities. These demands can lead to long-term care needs for the caregiver which are often left untreated due to lack of awareness of available support services and high out-of-pocket costs. These emotional and physical demands also place them at higher risk for morbidities such as chronic muscle strain, coronary heart disease, hypertension, lower perceived health status, poorer immune function, slower wound healing, and an increased risk of mortality (Greene et al., 2011; Jorgensen et al., 2009).

Economics

While most family caregivers willingly accept the caregiving role, an extensive body of research has found that not only are caregivers' physical and emotional health placed at risk, their financial security is placed at risk as well (Aging & Adult Services Division, MN Department of Human Services, 2011; Feinburg & Houser, 2012; Iecovich, 2008). The financial cost of caregiving often includes the need to pay for prescription medications, home modifications such as installing a ramp for a wheelchair-bound care recipient, or purchasing consumable supplies all of which can have a significant economic impact on a family and which reinforce why care providers are reluctant to spend funds on their own care needs. A study by MetLife (2011) found that women who are family caregivers are 2.5 times more likely than non-caregivers to live in poverty and five times more likely to receive Supplemental Security Income

(SSI), and that 23% of non-working and 20% of working female caregivers are providing financial assistance to the parent(s) in their care.

One might expect that the financial drain of caregiving would result in women increasing or maintaining work hours to insure steady income or to cover the cost of hiring a care provider. However, AARP (2015) reports that due to the physical, emotional and time demands of care giving, 33% of working women decreased work hours; 29% passed up a job promotion, training or assignment; 22% took a leave of absence; 20% switched from full-time to part-time employment; 16% quit their jobs; and 13% retired early. Reduced time in the workforce or complete withdrawal place additional strains on women's future retirement income. The resulting reduction in lifetime earnings in turn lowers contributions to pensions, Social Security and other retirement savings vehicles. This loss in retirement revenue places female caregivers at higher risk for poverty (AARP, 2015; MetLife, 2011).

Needs Identification

As the demands of caring for the care recipient increase, the care provider is likely to need support services, timely communications from the care recipient's primary care physician (PCP) and other key members of the care team, skills training, and access to resource agencies in order to avoid placing the care recipient in assisted or skilled nursing facilities. Castora-Binkley et al. (2010) found that information and referral services, individual counseling, support groups, training and education, family consultation and respite care offer caregivers needed knowledge, a sense of community, a sense of renewal, and that the services received were beneficial to both themselves and the care recipient. They further found that the utilization of caregiver services provides multiple benefits to the care provider's general health with reports of feeling better

supported and in turn having lower levels of stress, feelings of being over-burdened and less depressed.

An integrative study conducted by Silva, Teixeira, Teixeira and Freitas (2013) found that limited research efforts have assessed the needs of informal caregivers who care for the elderly living at home. Much of the available research contains conflicting opinions about what is needed by care providers (such as education about the care recipients' disease(s) and coping strategies for how to maintain one's own well-being) and how well these identified needs are actually being met. Washington et al. (2009) state that caregivers want: general knowledge about their loved one's disease and illness; specific knowledge on how to best care for their loved one; availability of services for their care recipient as well as themselves; and information about programs that offer financial guidance and support. They also identified that the timing of when this information is shared and the format of how it is communicated (i.e. with first person explanation or printed summaries handed over to them to read and interpret on their own) played an integral part in the care provider feeling supported in the role and responsibility of caregiving.

However, in contrast to this identified need, Lévesque et al.(2010) and Ng (2009) report that most support services tend to dictate to the care provider what assistance they are going to receive and fail to ask them what help is needed. When excluded from having an active role in the care plan, many caregivers will reject the help offered or stop services. Lévesque et al. (2010) and Ng (2009) suggest that when service providers supported the care provider through active listening; providing an explanation of the full range of support services available; and recognizing their contribution to the care team they fostered a higher sense of well-being in the care provider who was then able to transfer that self-view toward their loved one. A recent study by the AARP (2015) showed that only 32% of caregivers report the care recipient's PCP asked

what care assistance was needed in order to provide care for the care recipient and a mere 16% report being asked to share what they needed for their own well-being.

Furthermore, a study by the Aging and Adult Services Division of Minnesota's Department of Human Services (2011) showed care providers often have limited knowledge of the range and type of support services available to them or to the care recipient. In their study, the care managers (who are in large measure the holders of this knowledge), reported sharing resources with only 54% of the caregiver providers. The resources shared with care providers typically broke down to homemaker services (88%), home delivered meals (88%), adult day services (69%), respite care services (64%), companion care services (60%), and personal care services (59%). Only 36% recommended services specifically tailored to caregivers, such as caregiver training, and 30% recommended caregiver coaching or consultation. Significant to this paper is that only 46% of the care providers were included in developing the care recipient's care plan. In addition, the care managers never assessed their skills or knowledge on how to care for the care recipient's etiological needs nor were they offered the care recipient's etiology, and were not offered additional resources (support group, financial support, or respite services).

As many of these studies support, there is a direct relationship between the quality of care provided to the care recipient and the level of skills and information the care provider has about providing needed care as well as how to maintain their own well-being (Washington et al., 2011). Evidence-based caregiver training interventions such as the "Powerful Tools for Caregivers Program" have been designed to empower family caregivers in maintaining their own well-being (Won Won et.al, 2008). Although this program has proven to be a successful intervention strategy, there are multiple barriers to utilization. Barriers to utilization might include: the delivery of the program requires dyads of trained volunteer leaders whose

availability will determine the frequency and location of program offerings; the care provider needs to secure alternate care for their loved one; the care provider may feel conflicted feelings of anxiety and discomfort in relinquishing their care responsibilities to another; and the time of day/week the program is offered (Barbosa et al., 2011; Green et al., 2011; Ng, 2009; Pardasani, 2010).

There are very few identifiable studies on how the care provider becomes aware of support services available to their care recipient or for themselves. Previous discussions state that the care recipient's physician or case manager does not reliably share resources. Remaining options would be word of mouth, doing an internet search or learning about it in the media (paper, T.V., radio). Sometimes the local library or a local senior resource or activity center might also have knowledge of local services; but, as a study by Nolin, Wilburn, Wilburn and Weaver (2006) identified, even in communities with social service programs in place to assist older adults retaining their independence, many of the services were under-utilized and subsequently cancelled, because community members were unaware of the services or did not know how to access them.

Access to Information

Many state and county websites provide links to a Departments of Human Services. Those departments may provide information on resources available for transportation, financial assistance with food or utilities, or help completing Medicare/Medicaid applications (Greene et al., 2011). Internet searches engines can also provide a list of fee-based service providers offering in-home medical or non-medical care, respite care, or for-hire care managers. However, access to these resources requires the care provider to have access to a computer and to the Internet as well as knowing how to enter "key terms." Both the skilled and unskilled internet

user must also understand how to vet the information available such as: age or income restrictions; residency requirements; associated fees; terms of service and quality of care delivered. The answers to these questions are dependent upon the economic health of the community providing the service as well as public policy and, as such, will vary from community to community. Studies by Green et al. (2011) and Ng (2009) have found, the design and delivery of most support service programs for caregivers did not give much consideration to the caregiver's experience or on how to effectively deliver those services. The same is true for the manner in which one needs to conduct a data search on the web.

Barriers to Utilization of Services

Ng (2009) identified that barriers to service utilization included lack of transportation to a service, lack of awareness of the services, time commitments, cost of care, caregiver's sense of responsibility, lack of alternate care arrangements, and location of services (i.e. Adult Day Programs, Senior Centers, Assisted Living/Memory Care respite). Barbosa (et al., 2011) and Pardasani (2010) reported that turning the care of a loved one over to another can raise anxiety for both the primary care provider and the care recipient, as each may not feel they can trust the quality of the care given by a stranger. In addition, hard-to-reach caregivers who are homebound, illiterate, socially shy, have poor education and low-income are significantly less able to access and utilize most available services.

Another major consideration to service selection is that it entails more than having a name of a service provider. It requires the care provider to have an accurate understanding of: services needed by the care recipient; areas of support needed for themselves; an understanding of financial resources available, including a well-thought-out budget to insure the spend-out rate isn't faster than the life expectancy of the care recipient; awareness of legal limitations; required

documents for making decisions on behalf of another person; and last but certainly not least the skills, education, reliability, quality of care and their perceived trust and worthiness of the service provider (Barbosa et al., 2011; Pardasani, 2010).

METHODS

Data were taken from two target audiences. The first audience was comprised of informal caregivers who were invited to participate in a two-step process. The first step was to complete and return a short questionnaire (Appendix C) and the second step was to participate in an oral interview (Appendix D). The second audience was comprised of data collected in a customer relational database of citizens who visited a Resource Center in the Denver Metro Area. The data from the Resource Center served as a counter point to the personal interviews in that it offered insight into how a resource center was utilized by caregivers (e.g., who actively sought information about support services, the resources most requested, etc.).

Personal Interviews

Participants were recruited from a convenience sample that was sent an invitation via a direct email. The email included: an invitation to participate in the study (Appendix A); an explanation of qualifying parameters; the need to complete a short written questionnaire as well as participate in an oral interview; and information required for informed consent as approved by the Institutional Review Board at North Dakota State University (Appendix B). To qualify as a participant, the applicant was required to currently or recently (within the past five years) act as the primary care provider for an older adult age 65+. The care recipient could live in a residence separate from the care provider but could not be a patient in a nursing home, hospital or cared for by other paid medical staff.

In an effort to retain the privacy of those invited to participate, the invitational email was sent to the undisclosed addresses of a convenience sample of 60 individuals (comprised of men and women) living in the states of California, Colorado, and Oregon. Included within the invitation was the opportunity for “snowball sampling” in that the invitation to participate also

gave invitees the opportunity to share the invitation with their friends, neighbors or families who met the inclusion criteria.

Two questionnaires were developed to collect personal accounts of resource access and utilization. The first questionnaire (the written questionnaire) consisted of 20 questions (Appendix C). The written questionnaire was intended to capture demographics of the care provider and of the care recipient such as: age, gender; ethnicity, education level, economic range, relationship to the other, postal zip code, physical distance from each other, hours of care provided each day, and other time and financial obligations (because care recipients did not participate in the study, their information as provided by the care provider). There were two subcategories for capturing these data. The first subcategory, Summary of Person in Care, inquired about the care recipient's relationship to the care provider, type of chronic or terminal illness, and physical proximity to the care provider. The second subcategory, Primary Caregiver Experience of being the Care Provider, inquired how the care provider came to being in this role, prior experience as a care provider and other co-family or work commitments.

The second questionnaire, the oral interview (Appendix D), consisted of 35 open ended questions that provided the opportunity to explore answers in more depth. The oral interviews were administered to participants by the researcher. Out of respect for participants' time these oral interviews were completed within 60 minutes. Depending upon the geographic proximity of the participant to the interviewer, the oral interview was either conducted by phone or in person.

Twelve invitees responded with expressed interest in participating. Each of the respondents who expressed interest in participating was re-assessed to ensure they met the qualifying parameters of the study (had been or currently was a caregiver to someone over the age of 55 within the past five years). Eleven (11) respondents met the inclusion criteria.

Qualifying participants were assigned a unique subject number. The identifier was inserted at the top of the written questionnaire (Appendix C) as an added measure of confidentiality. It enabled the researcher to distinguish data among the various care providers without needing to use their name. Participants were given the option to receive the questionnaire as an email attachment or to receive a paper copy by postal mail; all but one participant opted for email. All were asked to return the written questionnaire within two weeks of receipt. There was a high attrition rate as only four of the eleven qualified participants returned the completed questionnaire. A subsequent reminder email was sent to the participants who had originally expressed interest in participating in the study; one participant expressed a desire to be removed from the study due to an increase in her caregiving demands, and no others responded.

The remaining four participants who had returned written questionnaire were contacted by email and given a set of three possible times to connect for approximately 60 minutes in order to conduct part II, the oral interview. Once a date and time was secured, each participant was either emailed or mailed (according to their preference) the oral interview questionnaire (Appendix D) approximately one week in advance of the scheduled interview. Sending the questions in advance allowed the care provider the opportunity to review the questions in order to formulate an answer but without over thinking their responses. The same identifier that was used on the written questionnaire was inserted on each oral interview prior to its distribution.

Only three of the four participants set up and completed the Oral Interview. All three participants were Caucasian women between the ages of 55-65. Two were only children and by default became the primary care provider to their mother; the third was the oldest of three daughters who took on the role as primary caregiver to her mother but whose two sisters provided respite care (the mother died last year). One participant lived in California, one in

Colorado and one in Oregon. Two of the women had obtained a master's degree and the other had completed two years of community college. The oral interviews with the participants living out of state were conducted by phone while the third interview was conducted face to face in the home of the care provider (who did not live with the care recipient). Each oral interview lasted 60 minutes. Before the interview process started each participant was reminded they had the right to refuse to answer any question without challenge and that their information would remain confidential and be blended with the other respondents. No one refused to answer any of the questions.

To identify the range of support services available to the care providers interviewed, either near their residence or the care recipient's residence, multiple Internet-based search efforts were made using Google. The zip code and key terms of both the care provider and the care recipient were entered by the researcher into the search engine. The key search terms used were: caregiver resources, caregiver support services, elder services, in-home services, and aging. The findings of available resources were then compared against the resources utilized by each of the three participants from the personal interviews.

Resource Center

The Resource Center is located inside the main branch of the local public library. It opened its doors, as a pilot program, on September 2, 2014. It is open 20 office hours per week with the intention of serving citizens aged 55+ and their care providers with information on available resources. Those in need of resources and referrals can access the center by visiting the office or calling during office hours or by sending an email. Each resident is allotted 30 minutes of personal consultation. In addition, resource brochures on these same services are available on

display racks outside of the Center and can be easily accessed by anyone in need of information during the library's expanded hours of operation.

Two inventory tracking systems are used to identify which service needs are in the highest demand. Visitors are asked to complete an intake form which asks for their name, address, phone number, email address, age range, gender and type of general resources (food, insurance, housing) needed. The Center Staff interviews the visitor and through the process of discovery, helps the visitor identify resources that may be helpful. Those resources are then recorded on the same intake form previously completed by the visitor. This information is then entered into a database. The brochures taken from the display racks outside of the center are set out and restocked in batches of ten. Each time a given brochure is re-stocked the batch is entered on an Excel spreadsheet with a cumulative total by brochure (service type) and a grand total of material taken. The data pulled for the current paper was based upon information recorded on the database and on the Excel spreadsheet starting September 2, 2014 (when the Center first opened) to April 30, 2015.

In the first 8 months of operation, the Center saw an average of 32 visitors per month. Women were approximately three times (n=165) more likely to request assistance from the staff at the center than men (n=58). Word of mouth was the highest ranking method reported by women as to how they learned about the Center, in second rank were those who encountered the center while visiting the library, and third was reading about it in a flier or brochures. For men, the most frequent method for learning about the center was while visiting the library, then a news article, and last was by word of mouth.

The top five resources requested among care providers were for information on house setting options (27%), including non-medical in-home services to support aging-in-place or how

to select a retirement/assisted living community; social services available in the community (15%); local transportation services (14%); how to apply for Medicare/Medicaid (10%); and education about support for medical conditions (9%) such as heart disease, Alzheimer's, macular degeneration or kidney disease.

The Resource Center does not provide direct services but rather provides referrals to local agencies and service providers who do provide those services. Therefore, in order to determine if and how visitors to the center used the resources provided, a follow-up survey (Appendix E) was conducted in which randomly selected visitors were contacted by phone and asked to participate in a service utilization survey. The survey included a yes or no response to whether they had been able to contact or receive support from any of the resources provided to them by the Resource Center. Participants were also asked to identify the name of the service provider(s), and then to rate the quality of service provided by each referral on a scale of 1 to 5 (with 1 low and 5 high). Two follow up efforts were made. The first was three weeks after the visitors' received the resources, and the second was conducted three months later. The follow-up survey did not screen between visitors seeking support services for their own needs or on behalf of another as care providers' request could fall into both categories. For the purposes of this paper, only the survey results of adult children who sought resources for their aging parents were used.

FINDINGS AND DISCUSSION

The focus of this paper was to examine how a small sample of informal caregivers sought and utilized support services. Three data sources are the basis of this paper: current research (literature review); oral interviews of care providers; and inquiries made at a community Resource Center.

Oral Interviews and Current Research

The three oral interviews conducted with three daughters acting as the primary care provider to an aging parent (in this case their mothers). Consistent with the findings in a caregiver study conducted by AARP (2015), each of the participants was in her early 60s and caring for a mother in her 80s who lived on her own. As identified by Reinhard, Friss-Feinberg, Choula, and Houser (2015), these women did not abandon their caregiving responsibilities because of employment but instead coped, to the best of their abilities, with: the combined pressures of caring for their mother; their need for income; reliance on often inadequate public programs; and fewer employment-related benefits. The caregivers in California and Colorado each held Master's degrees and earned close to six figures annually. The caregiver in Oregon had completed two years of college and was not employed outside of the home.

The experiences of these three care providers were similar in some circumstances and quite varied and unique in others. The caregiver in California and the caregiver in Colorado were only children and both of their fathers had died many years earlier, leaving each of them in the role of sole support for their aging mothers. The caregivers from California and Oregon had a circle of moral support from their husbands and adult children. The caregiver in Colorado was single and childless but did have a circle of friends who offered a high degree of moral support and would sometimes provide respite care. The caregiver in Oregon was the oldest of three

sisters, whose father had also been deceased for many years. She and her husband lived closest to her mother placing her in the role of primary caregiver. Her two younger sisters alternated in providing her respite from her care giving duties in three-to-four week stretches once per year.

Each caregiver's care recipient suffered from different diseases, which influenced each of their roles as caregiver. The mother of the care provider from California was in early to mid-stage Alzheimer's when the daughter stepped into a more active role as her mother's primary care provider. The mother of the care provider from Colorado suffered from MRSA, rheumatoid arthritis and Type II Diabetes. She relied on mobility devices (walker and wheelchair) to get around and had forfeited her driver's license. The mother of the care provider from Oregon suffered from late-stage lung cancer.

Added to the complexity of care giving was the geographic proximity of the aging mothers to their daughters as well as the daughters' work-life commitments. The California caregiver was married, worked full time as a consultant and needed to travel two to three times each month for two or three days at a time. Her mother lived across the country in Florida. The Colorado caregiver was single and self-employed. Her work required she meet with her clients at hours that suited their time availability versus normal 9-to-5 hours. Her mother lived in the same town (15 minutes by car). The Oregon caregiver was married and not employed outside of the home. Her four children were all grown living on their own; three lived nearby and one lived out of state. Her mother lived in a rural setting located a 30 minute drive from the daughter's home.

Needs Identification and Access to Information

Declinations in health and corresponding increased need for assistance in dressing, bathing, toileting and managing daily affairs (paying bills, transportation, cooking and making

sound decisions) were the motivating factors for each daughter in assuming the role as primary informal caregiver to her mother. The California care provider was advised by her mother's PCP that her mother had dementia and needed to be placed under full time care as she was no longer able to make rational decisions about independent activities of daily living (IADL). When the care provider was asked, during the oral interview, if her mother's PCP had provided her with a list of local resources able to assist her in identifying and contacting support services or resources available in the local area, she said no resources had been shared. This lack of sharing needed and available resources is consistent with the finding by Green et al. (2011) and Ng (2009).

The physical health and mobility of the mother of the caregiver in Colorado was in a progressively declining state. The daughter provided care support between 25 to 40 hours per week. Because the mother wanted to remain in her own home, the daughter was required to transport her mother to a growing number of doctors' appointments, cook her mother's meals, do her mother's laundry, housecleaning, take care of her mother's two dogs, and mow her mother's front and back lawns. The daughter also made regular daily visits to her mother's home: once in the morning and once again in the evening. The growing demands on the daughter's time negatively impacted the time she had available to run her business. While her self-employed status awarded her the flexibility to reduce her hours; she did so at the cost of losing income. She shared that her efforts at using the Internet to find services that could share the burden of caregiving (in-home medical, non-medical, and transportation) did not provide viable results.

The care provider from Oregon helped her mother through the late and final stages of lung cancer. As the mother's ability to complete independent activities of daily living (IADL) as well as activities of daily living (ADL) decreased, the daughter stepped in and provided

increasing assistance. Unlike the other two care providers interviewed, she reported feeling very supported in the process of caring for her mother. This was in larger measure due to the fact that her mother, who had worked for many years as a care provider herself, was familiar with support and care services available to her due to her low-income through a state program called Aging and Disabilities Program. As the care provider shared, because her mother was familiar with available services she had previously created a care plan for herself which eliminating the need for her (the daughter) to find resources for her mother.

Barriers to Service Utilization

Selection of services varied between each of the care providers and was based upon their respective mothers' etiology and the degree of support from human service providers in their relative communities. Through an Internet search, the California care provider found a national agency that offered in-home non-medical care. She hired a 24-hour care provider to stay with her mother in her mother's home in Florida. Even though the daughter knew her mother had Alzheimer's she did not seek guidance from the Alzheimer's Association. When asked why she didn't pursue this resource, she offered she felt it was a service for those with less education than she had and who needed more assistance in understanding the disease. Her reactions are consistent with the study by Raviolo, Laakkonen and Pitkälä (2011). In spite of her mother having an around-the-clock live-in companion, her mother's challenging behaviors continued to escalate. The daughter felt relocating her mother to an assisted living facility near where she and her husband lived in California would give her more effective oversight of her mother's care and behavior. The facility she chose was recommended by one of her neighbors. Again, she did not contact the Alzheimer's Association to get tips or advice with regard to moving her mother across the country or in selecting an appropriate housing option. Within three months of moving

her mother into the assisted living facility in California, she was informed they could no longer provide care to her mother.

As she describes it, ‘quite by chance’, while visiting her mother at the assisted living facility she encountered a presentation about Veteran Administration benefits for which her mother was eligible due to having served in the Coast Guard during WWII. The VA Hospital was located about 40 minutes from the daughter’s home. Both of these word of mouth and random exposures to available resources support findings from Nolin et al. (2006) that many in need of services are not aware of those available in their community. The daughter shared that learning about her mother’s eligibility for VA services and her admissions assessment was serendipitous. The person conducting the admissions assessment at the VA had also served in the Coast Guard. When he saw that her caregiver’s mother had served under the same branch of service, he gave her application preferred status saying, “They take care of their own.” Her mother was accepted and admitted into the Memory Care unit of the VA hospital and continues to live there today.

When asked what efforts she took to take care of her own health, the care provider from California answered (with a laugh) that she tried to get out walking for 30 minutes each day in her neighborhood, go to yoga with her husband one to two times per week, and spend time with her friends. In ranking her top five preferences for identifying resources she listed 1) word of mouth; 2) the Internet; 3) medical personnel; 4) community resource center and 5) other.

While the care provider in Colorado shared that she and her mother have had many discussions about the possibility of her moving into an assisted living facility, her mother, like the majority of older adults, wants to age-in-place in her own home (Green et al., 2011; Ng, 2009). Although she had the financial means to cover the related expenses, her mother also

resisted suggestions of hiring skilled nursing to tend to her wound care on a regular basis even though she did allow a nursing service to come and tend to her needs, when the daughter was on a trip. The daughter reported that the mother found the appointment windows given by the nursing service restricted her ability to make other social or medical appointments even though she rarely left her home (even with her daughter). The mother's resistance to accepting outside help may in part be due to cultural values (the family emigrated from Holland when the daughter was 8 years old) or it could be because she feels anxious about having someone, other than her daughter, provide her care (Barbosa et al., 2011; Diefenbach, Tolin, Meunier & Gilliam, 2009; Pardasani, 2010).

The daughter shared that she spent three hours conducting a search on the Internet in hopes of finding a transportation service that could transport her mother to and from the doctor's each week so that trained medical staff could provide the needed wound care. In her hours of online searches and subsequent phone calls, she learned that her mother either lived outside of service geographic boundaries or that her annual income exceeded the income caps needed to qualify for government (local and county) subsidized transportation services. She also learned that the round trip cost of a taxi cab would, overtime, be cost prohibitive regardless of the reliability.

Pressure placed on the daughter to coordinate and provide all of the in-home medical and non-medical care for her mother has, according to the daughter, negatively impacted her ability to continue running her business. Her lost revenue has depleted her financial resources and savings for her own upcoming retirement as well as leaving her feeling stressed and impatient toward her mother. As cited in the studies by MetLife (2011) and AARP (2015), the loss of revenue and ability to save for her own retirement places this caregiver at higher risk for poverty

when she elects to retire. As a single woman, she also does not have access to spousal financial resources. The growing frustration of not being able to find resources that her mother was willing to accept or qualified to receive places her own health at risk which in turn may jeopardize her ability to care for her mother (Feinberg & Houser, 2012).

The care provider from Colorado also shared that she was unsuccessful in finding a caregiver support group that wasn't focused on a specific illness (i.e. COPD, kidney disease, Alzheimer's, etc.) or at finding a caregiver skills training course. Although she had found a 'general' caregiver support group listed online, when she contacted the facilitator, the facilitator informed her that training was discontinued due to lack of interest. The facilitator was not able to recommend another active support group. The caregiver also inquired about evidenced-based skills training course called Powerful Tools for Caregivers. However, it was not available in her community due to the lack of trained course leaders available to offer the course.

When asked what efforts she took to take care of her own health she shared that when feeling distressed she puts off her exercise routine until the evening but that rarely turned out to be beneficial because she often found she was too tired at the end of the day. She did acknowledge that while her own primary care provider was aware of her role as her mother's primary caregiver, she was not asked if she was experiencing any stress or strain from the role or directed to any support services. In ranking her top five preferences for identifying resources she listed 1) Internet; 2) word of mouth; 3) medical personnel; 4) community resource center and 5) newspaper.

In contrast to the experiences of the caregivers from California and Colorado, who encountered multiple barriers to service utilization, the low income status of the care recipient in Oregon as well as her familiarity with the services available to her through the state's Aging and

People with Disabilities Program eliminated the challenges related to identifying and locating services. The daughter shared: “Because my mom worked for so many years as a caregiver herself, she had everything laid out for me; I didn’t really need to go search for services on my own” (Caregiver from Oregon). Because she didn’t need to seek out resources, she did not rank a preference for where she sought to learn about resources. However, it is important to note that this state program does have income restrictions which could be a barrier to service utilization by other residents with higher income ranges.

Stress and Strain of Service Utilization

As the discussion above highlights, stress and strain of family based caregiving is made more complex by the fact that the majority of older adults avoid creating a care plan in advance of a crisis. When care decisions are made in moments of crisis, the burden of making major life and health decisions squarely on the shoulder of the informal care provider (Kane, 2001). The informal care provider’s ability to implement support is additionally challenged by the fact that a high percentage of older adults receiving in-home care often suffer from generalized anxiety disorder as they are afraid their chronic illnesses will escalate to their needing to be transferred to a nursing home (Diefenbach et al., 2009). As exemplified by the experiences of the care provider in Colorado, a circular pattern exists whereby the care provider searches for and finds support services that are in turn refused by the care recipient places additional strain on both the care provider and the care recipient (Diefenbach, et al., 2009).

The care provider from California had a chronic medical condition of her own. Having to transfer her mother to another state, encountering unexpected challenges and limited service delivery at the assisted living facility near her home, and then having to complete the lengthy process of moving her mother a second time into the VA hospital led her to seek counseling for

herself. Her response that she felt the counseling ultimately assisted her in developing better coping skills aligns with the findings by Castora-Binkley et al., 2010. The counselor directed her to the Alzheimer's Association so she could access resources about the disease, care management and the option to join a support group. She did attend a support group a few times. When asked why she stopped utilizing the support services offered by the Alzheimer's Association, she shared it was in part due to the fact that she felt the group 'told' her what kind of assistance she needed, rather than asking her what she felt she needed. This is in keeping with the findings by Lévesque et al. (2010) that being asked rather than told yields greater service utilization. Consistent with findings by Crespo & Fernandez-Lansac (2014) that unresolved anger toward a parent can contribute to caregiver strain, the daughter also shared she harbored unresolved anger toward her mother for her past behaviors and still felt some resentment toward her that she wasn't yet ready to address.

The care provider from Colorado shared that much of her effort in securing care for her mother was a constant back-and-forth battle with her mother's PCP who assigned her the task of cleaning her mother's wounds, a skill for which she had no formal training. She also spent endless hours searching the Internet for respite care, transportation, support groups, and home services offered through the local Area Agency on Aging, all of which have barriers to utilization due to eligibility requirements (e.g., income caps, hours of service, insurance restrictions and cost of services). An additional challenge for this care provider is her mother's unwillingness to accept assistance from someone other than her. This resistance is adding strain on the daughter. From a purely academic perspective, this dyad could be at risk for abuse from daughter toward the mother and vice-versa (Crespo & Fernandez-Lansac, 2014). The daughter also shared that her efforts to identify resources such as a caregiver support group or skills training course (both

of which are identified as key resources by Barbosa et al., 2011 and Pardasani, 2010), resulted in dead ends. She expressed great frustration that there was not an organized site that listed local resources for the aging including transportation, skilled nursing, in-home non-medical, respite care or caregiver skills training that included next to each service provider's name, all related costs and usage restrictions (income caps, hours of service, geographic proximity, costs). She share that having such information would have saved her from spending hours trying to identify available services. She also shared that on multiple occasions a service provider re-directed her to several other agencies creating what she called a 'circular loop' in resulted in her having no needed support.

The caregiver from Oregon expressed feeling very little stress and strain in her role as primary caregiver to her mother. She shared that she found a great deal of comfort in filling the role and that she felt it was her duty as a daughter. She received a great deal of support from her husband who kept the home-front in order but she also called on the support of her local church and prayer. As she didn't work outside of the home, she shares she did not feel she had competing demands on her time. In addition, the high degree of support she received from the state's Aging and Disabilities Program made her feel very supported in the role as primary caregiver. The program assigns a care manager to each care recipient to provide oversight of the care recipient's overall health plan, and executes changes in support services as needed. The program also offers each care recipient the option of hiring their own care providers, including family members. As a 'hired' care provider, she was compensated at the going minimum wage in exchange for which she had to submit a weekly report to the care manager with the details of care given and hours spent with her mother. The program also gave her access to online as well as on-site training at local facilities on a range of topics including caregiver skill building (e.g.,

coping skills, basic first aid, CPR, medication management, identifying and collecting advanced directives, insurance coverage, and financial management).

The experiences of the caregivers from California and Colorado support AARP's (2015) findings that, in spite of the proximal relationship between the PCP's of both the care recipient's and the care provider's, they fail to offer resource information. Both of these care providers also had to learn about available resources through word-of-mouth or trial and error which as the care provider from Colorado shared "was frustrating and led to dead ends." It is important to point out that a list of resource providers alone does not offers a means for vetting the quality or reliability of a given service such as is possible through an Ombudsman or state managed business ranking of service or accreditation programs like the Community Health Education Program (CHAP). As a study by Kane (2001) highlights, the challenge with word-of-mouth recommendations is that satisfaction with a service is subjective to an individual's personality. Any given service may be viewed positively by one person and negatively by another.

The care provider from Oregon shared that acting as her mother's primary (informal) care provider, she was well supported by her mother's care manager who kept her current on her mother's changing needs and included her in the decision making process. She also reported that the access to a wide range of skills training (how to properly conduct a transfer to financial management) made her role easier. This same finding is reiterated in the manner in which the dementia care staff at the VA hospital created a sensitive, proactive and inclusive care team that included the mother's family in the decision making process. The care giver from California shared that through regular phone calls and her bi-weekly visits, she is kept abreast of changes in her mother's behavior and over all well-being and like the care provider from Oregon, is always included in decision making related to her mother's level of care.

These diverse first-hand experiences of being an informal care provider illuminate how the health of the relationship between the care provider and care recipient, the ease or difficulty of gaining access to resources, and the manner in which information is acquired (i.e. where it is found, being asked what is needed versus being told what you can have) each play an integral role in the selection of service utilization and the related degrees of stress and strain.

Economics

The resources for covering costs of services for the three participants were again as varied as the needs of their mothers. The care provider in California was relying on her mother's financial resources (Social Security, Tri-Care, savings and the proceeds from the sale of her home) to cover the cost of the room and board and hands-on care. While she did cover the out-of-pocket cost of her mother's prescription drugs and personal items (toiletries, depends) she was concerned that her mother's funds might not last up to her death. One of the regular processes she followed each month was to review the monthly statement from the VA. In this process she often identified overcharges as well as charges for unnecessary services.

According to the care provider in Colorado, her mother had ample funds to cover the cost of living in an assisted care facility. Her refusal to spend her funds on her own care could be due to her generation (i.e., the generation who endured the Great Depression and experienced Nazi occupation during World War II) who are typically reticent to spend money. Her resistance to moving might also be her preference to age in her own home or because of an anxiety-based preference that her daughter take care of her. However, the complexity and time demands of her care needs have interfered with her daughter's ability to run her own business which in turn has reduced her daughter's income and ability to save for retirement (AARP, 2015).

The low income status of the care recipient in Oregon made her eligible for the state's Aging and Disabilities Program, which is partially reimbursed by Medicare and Medicaid (CMS). The program paid for the time the Colorado care provider and two her sisters cared for their mother, the skills training classes and for the services of the care manager. The mother was required to pay \$120 per month to cover the cost of around the clock care during the final stages of her cancer.

The Resource Center and Literature

The purpose of the Resource Center was to connect older citizens and their caregivers to support services offered by the city, county, state and federal governments as well as by non-profit agencies. The visitors who came to the center in search of available resources were seeking information on behalf of themselves, a spouse, a neighbor or for their aging parents. One segment of the community who came to the Center, were adult children looking for resources and referrals for their aging parents who lived in the community. In keeping with the study by AARP (2015), the adult children who made inquiries were primarily, but not exclusively, daughters or daughters-in-law who were employed in the labor force and still raising their children. According to data collected by the Center, about 15% of the adult children who contacted the Center lived out of state. Consistent with findings by Nolan et al., (2006) the geographic distance between the adult children and their aging parent added to the complexity of finding needed care that addressed their concerns about the quality of care being provided by a stranger that they could not directly observe. As identified by Pardasani (2010), many adult children also expressed experiencing conflict between the need to find care for their parent and having the time or financial flexibility to offer the care themselves.

Needs Identification, Access to Information and Service Utilization

The Center staff asked the adult children to complete an intake form used to identify what type(s) of services they were seeking (food, transportation, assistance with home maintenance, care services etc.) on behalf of their parents. In order to supply the care provider with the full range of possible services available to them or their loved one, the Center staff conducted a disclosure interview. The purpose of the interview was to determine if the care recipient might need specialized services due to any existing chronic illnesses; cognitive loss or physical limitations. The Center staff typically could identify more services than the family was aware existed, which is consistent with findings from Green et al. (2011) and Nolan (2006). The Center staff also assisted the care provider in identifying any service restrictions or eligibility requirements which sometimes narrowed the range of possible resources. The Center staff also provided visitors with a list of questions they could ask of each service provider in order to determine whether the provider's program and staff could meet their parents' specific needs and wants.

On the intake form, there was also a section asking the visitors if they would be willing to participate in a follow-up survey. Those that agreed received a follow up call by the Center staff. The visitors who were contacted by the Center staff were asked if they had used any of the resources provided and if so, what was their perception of the quality of service offered by the agency/provider (Appendix E). Based upon the secondary data collected by the Center staff, and subsequently shared for purposes of this paper, 67% (8) of the 12 adult children who participated in the follow-up survey reported contacting the resources provided. Those who had not utilized the referrals most frequently stated it was because their parent's health had taken a sharp decline and they needed more urgent coverage.

Barriers to Utilization of Services

The adult children who contacted the Resource Center for caregiver resources encountered multiple barriers to service utilization including: lack of awareness of service; ability to access a service; service restrictions; and having the necessary resources to utilize the services. As Kane (2001) offers, lack of awareness of available services is partly due to the lack of prior need for the service (we typically seek out information on an as-needed basis). Their experiences are confirmed by Pratt (2016) who offers that the lack of uniformity of service identification and advertising placement which makes it difficult to know what terms to use when asking others or conducting a search on the internet (p. 28-29).

Common utilization barriers among the government agency services distributed by the Resource Center included restrictions due to age, income levels or geographic proximity. Because these restrictions vary by agency, geographic location and the funding agency, each inquiry is unique to the individual in need. During the Resource Center's follow up efforts to find out the usefulness of the resources it shared, multiple visitors reported that the agency they were referred to informed them of additional restrictions of ineligibility or sent them to other resources. Other utilization barriers were: the lack of a means of transportation to a given service provider; the hours services were offered; and the geographic distance to the service (Green et al., 2011; Ng, 2009). The hours of service offered by the Resource Center (20 hours a week Monday through Friday) were a barrier to working adults who worked during the weekday and were only available to access the center after work hours in the evening or on a weekend.

Even though the Resource Center had access to a full menu of service agencies to share with care providers, they were targeted toward supporting the needs of the care recipient and not the needs of the care provider which, according to Ng (2009), is a barrier. In addition, access to

specific services offered through the Resource Center was limited by whether or not the service provider or agency offered a marketing brochure that could be taken from a display rack during the hours the Center was closed. In addition, as the Center was a government-funded office, the Center staff only shared fee-based service during a direct consultation (in person, by phone, or email).

Economics

The adult children who came to the Center requested and were given a menu of possible resources, including in-home medical and non-medical care, so that they could select which resources they needed and or could afford (Green et al., 2011; Ng, 2009). Most were relying on their parent's insurance policies (e.g., pensions, Medicare, long-term life), savings accounts, or assets owned by their parent. As the Resource Center did not provide direct service, data were not collected to identify which of the resources shared were actually utilized or how the families planned to cover care expenses. According to AARP (2009), Iecovich (2008), and Minnesota Department of Human Services (2011), the primary care provider often covers many out-of-pocket expenses (e.g., prescription medications, home modifications, or purchasing consumable supplies).

Oral Interviews and the Resource Center

As the caregivers in this study demonstrate, managing care for a parent can be stressful. Members from both groups (the care providers interviewed and those who contacted the Resource Center) had to find a balance between assuming the role of “the adult” to an aging parent and the demands of work and other family responsibilities. Both groups also initiated their search efforts in reaction to a dramatic change in their parents' health (onset of a chronic illness), physical injury (broken hip, onset of osteoporosis) or evidence of their physical frailty or

cognitive impairment (dementia) that interfered with their ability to continuing tending to their homes or their own care needs. The only participant in the study who had secured services based upon a predefined care plan was the care provider from Oregon; all other care providers were reacting to the immediate needs of their parents (Kane, 2001).

Some care providers expressed harboring anger toward their parent for childhood wounds, others for their parents' resistance to accepting hired care, and others for their parents' lack of planning ahead. Lack of awareness about what types of services are available and uncertainty about how to pay for needed services adds to the emotional turmoil of being care provider. The care provider from Colorado expressed feelings of value and gratitude for the opportunity to help their parent in their time of need. This group expressed concern that the quality of services provided by someone other than themselves would not meet the needs of or satisfy their aging parent (Nolan et al., 2006).

Needs Identification, Access to Information and Service Utilization

Identifying what types of support and services are needed requires the caregiver to fully understand the care recipient's diagnosis, etiology, a contextual understanding of the care recipient's values, and care preferences. Both sets of caregivers (those from the oral interviews and those from the Resource Center) became aware of available services primarily through word of mouth. While this is in keeping with the data collected from the Resource Center, it is important to see this in context with Kane's (2001) finding that such recommendations can be experienced quite differently according to an individual's perspective. This finding also supports the studies by Iecovich (2008) and the Minnesota Department of Human Services (2011) that report that health care providers are not providing caregivers with resources.

Although the adult children in this study were relatively familiar with the Internet, most were not familiar with key search terms to use to retrieve data on either government or fee based services. According to Pratt (2016), long-term care services have been in a constant state of change due to changes in demand, available resources to provide service, and reimbursement rates (p. 35). This adds stress for care providers in determining available and affordable support services able to address their aging parents' constantly changing needs.

The care providers in California and Oregon were assisted in selection of service needs and utilization through heavily structured care programs, offered respectively by the VA and the Oregon State Insurance Program. Both programs assign a trained care manager to provide oversight and to bring in additional resources to both the care recipient and the care provider. In both situations, the role of care manager alleviates effort, stress and the need to identify, vet and determine the next course of needed action. In contrast, the care provider in Colorado, like the adult children who contacted the Resource Center, did not have access to a care manager, a primary care provider or a gerontologist willing or able to guide them in the process of determining service availability and appropriate selection. Instead they had to expend a great deal of effort (time and mental strain) in identifying and determining among a constantly changing pattern of service offerings which one's best met their needs on the basis of eligibility, affordability, accessibility, and availability.

Barriers to Utilization of Services

Lack of awareness about a service was the most frequently cited barrier to service utilization among both groups. As both the care provider and the visitors to the Resource Center shared, even when they had contact information for a service provider, their requests for information and assistance were often circular in their being referred to other providers. Among

the two groups in this study, additional reasons for lack of service utilization were: resistance from the parent in the type of services selected; having someone other than the primary care provider or other family member deliver services; hours of service offering; cost of services; or the need to find alternate care for the care recipient while they participated in support services (Ng, 2009).

Economics

A common goal for all care providers (those from the interviews and those who visited the Resource Center) was to find services that could be covered by their parents' insurance policies, savings, pensions, or assets for the duration of their lives. However, like the care providers in California and Colorado, a certain portion of expenses such as prescription medications, application fees, medical equipment (not covered by insurance) were paid for by the adult children (AARP, 2009; Iecovich, 2008; Minnesota Department of Human Services, 2011). Due to the limited scope and number of follow-up surveys with the adult children who came to the Resource Center, it is impossible to accurately determine how many from this group paid for a portion of their parents' health care needs and how many were negatively impacted financially (like the care provider from Colorado).

As the three comparisons between the oral interviews, Resource Center and literature review support, the role of the informal caregiver is challenged not only by providing hands-on care but also in the need to identify and coordinate services for the care recipient and themselves. The current infrastructure available for identifying service availability is in many ways a key barrier to service utilization.

Discussion, Limitations, and Future Research

As multiple studies support, the role of the informal caregiver is challenging (Lévesque et al., 2010; Ng, 2009; Nolin, 2006; Reinhard et al., 2015). As this paper illuminates, the three sources of data (research, interviews and visitors to the Resource Center) identify common experiences: the lack of awareness, access and guidance among available services leads to frustration, stress and strain for caregivers. Furthermore, a significant contribution to the challenges faced by informal caregivers is the process they must follow in identifying and utilizing services either for themselves or for their care recipient. Although the studies by Green et al. (2011), Nolan (2006), and Ng (2009) all report that primary care physicians are in a key position to share care resources with their patients; according to the participants in this paper, this important step is still not being taken.

Gaps in Service

Consistent with research by Green et al. (2011), Ng (2009), and Nolan et al. (2006) the three data sources all reported that lack of service utilization was in large measure due to lack of awareness of available services. A key contributor to this barrier is the inconsistent use of nomenclature among care agencies which makes it nearly impossible to find and compare available services (Pratt, 2016, p. 231). In an effort to assess for differences between support services available to each of the care providers interviewed versus those they utilized, the researcher conducted an Internet search looking up different categories of potential resources available in each of the zip code areas of each care provider and care recipient in California, Colorado and Oregon. The key terms used were “senior services”, “home care services”, “memory care”, “and assisted living facilities”, “transportation services for seniors” and

“Veteran Services”. These broad range terms were selected with the intent of receiving the higher number of hits.

In keeping with the studies cited in this paper, there was an inordinate amount of inconsistency in the nomenclature used among service providers which not only added to the challenge of identifying resources but also made it nearly impossible to compare like services on an apples-to-apples basis (Gonyea, 2013; Pratt, 2015, p. 43). Embedded in each web page, along with links to a specific care service, are multiple marketing ads, while other links are to an organization’s Facebook page. This unorganized method for trying to identify viable services is visually confusing and can consume a great deal of the care provider’s precious time as they try to sort out ads from services.

In addition, when going to a service provider’s web site it is often difficult to find their service requirements, restrictions or pricing as this information is often embedded within the website or not listed at all. Not having access to a means for identifying if the service is one they can utilize consumes even more precious time for the care provider. While this type of resource is available at the state level or county level it is not offered with any consistency across all fifty states or all counties within a state nor do these listings use uniform nomenclature; making it difficult for the average consumer to locate this resource via an online search. In addition, listings that do exist do not include details of the eligibility requirements or a ranking of the quality of the service offerings.

Services Available, Services Utilized

The online search results for California represented services available in two communities in Northern California. Both areas showed the highest number of services across all categories especially with the number of fee-based services in senior services, home health,

assisted living and memory care facilities but only one result for government and one result for a non-government organization. But as the searches were embedded with marketing ads, the California Caregiver's reliance on word-of-mouth recommendations in selecting an assisted living facility for her mother was a more efficient use of her time in spite of the subjective and personal nature of one's perspective of any experience (Firbank, 2010; Kane, 2001).

The online search results for two large suburbs in Colorado showed a higher number of senior services offered through the government and like the zip codes in California, a high number of fee based service providers across all categories. This search had the highest number of assisted living facilities, which the care recipient did not want to utilize. Transportation was one of the key needs identified by the care provider and while government, non-government and fee-based providers were identified, the caregiver shared that her mother did not qualify for the government and non-government services nor could they afford the fees charged by the fee-based providers.

The online search results for two smaller communities in Oregon had the highest number of government subsidized senior services as well as the lowest number of fee-based senior services, most likely due to the fact that State of Oregon is proactively addressing service needs for their elderly population. The results for these two locations also had the highest number of assisted living facilities but the fewest number of memory care facilities. The large presence of the government services listed in the web search underscores the range of support offered to the elderly. It is through the state's Aging and Disabilities Program that informal care providers are provided with access to skills training and awarded financial compensation for their time spend as a primary caregiver.

The number of hits recorded for each care team provides a picture of the complexity involved in trying to decide which services will best meet the needs of the care recipient and the care provider. It also helps explain why the care provider in California relied on word-of-mouth referrals, why the care provider in Oregon was so appreciative of her mother having care resources in-place and why the care provider in Colorado felt so frustrated in her failed efforts of trying to find resources on the Internet.

New Opportunities

The literature review, oral interviews and data from the Resource Center all identified the following opportunities for improvement and potential windows for new services: uniform service identification and access parameters; a shift in our culture's view of aging to extend beyond functional decline by including mental health and quality of life needs; a lack of services to assist care providers in creating a comprehensive care plan as well as services that assist adults in pre-planning one's long term care needs ahead of a crisis.

Because of the lack of a national oversight of Health Care services, each state has the freedom to determine where and how to allocate their funding and efforts for public needs. The intent is to allow each state to spend their dollars on public services most needed by their immediate constituents. However, this separateness promotes the lack of consistent nomenclature used among services and supports across geographic boundaries. From an anecdotal perspective, care providers and the aging in general could benefit from all states being federally mandated to publish an annual state-level directory that lists long term care services available on a county-by-county basis. The directory should list agencies and service providers by category of services they provide (home assistance, home health, assisted living, skilled nursing, rehab centers etc.). Agency contact information, current fees and any eligibility

requirements or restrictions (age, income, geographic boundaries and accepted insurance) as well as hours the service is available would be included for each service listed in the directory.

According to Lévesque et al. (2010) access to this type of directory would expand care providers' understanding of what services are available, which services best support their family's needs, and identify any barriers to utilization. Having access to the different types of services available in a specific area and the local cost for those services would be quite valuable to those who are considering relocating their aging parents (or themselves) to a different county or to a different state.

In order to insure the offering is available to economically and educationally diverse populations, who may not have access to a computer or to the Internet, the summary should be available in a well-organized web site as well as in hardcopy printed format. As confirmed by Washington et al. (2011) knowledge of this resource should be shared with the primary care provider and care recipient by the Primary Care Physician when they first identify the care recipient's need for assistance due to functional decline, mental health issues, or bereavement. The directory should also be offered through social service agencies and public libraries.

The role of the informal caregiver is more than just assisting older adults in completing daily activities. It also requires administering medical care, serving as an advocate and making complex decisions about another person's health and quality of life. The complexity of this role strongly suggests all care providers would benefit from having access to a Care Manager who would assist informal care providers in creating a family-centered plan that insures a holistic view of the needs of the care recipient as well as their own needs (Lévesque et al., 2010; Reinhard et al., 2015).

Based upon issues identified in this paper a support services program would extend to informal caregivers guidance on how to support the functional decline (biological and cognitive) of their care recipient as well as offer guidance and resources that address mental health concerns. Diefenbach et al. (2009) and Smith et al., (2011) agree there is a prevalence of generalized anxiety disorder and depression among older adults as they move through cycles of loss and grief that are natural components of aging (retirement, chronic illness, bereavement) and that the elderly using in-home care services are at higher risk of these mental health issues. From an antidotal view, scant regard seems to be given to supporting the mental health needs of either the care recipient or the care provider. Because the emphasis of care is focused on biological or cognitive declines, too little attention is given to services and resources that insure quality of life: choice, autonomy, relationships, enjoyment, engagement in meaningful activities, safe and aesthetically pleasing living environments and spiritual well-being (Iecovich, 2008; Kane, 2001).

The benefit of offering caregivers the support of a care manager is well-supported by the experiences of the care providers from California and Oregon who both had the benefit of assistance with care selection and utilization. Both care providers acknowledge that this level of support reduced their levels of stress and strain. One cannot help but wonder how such a service might have altered the experiences of the care provider from Colorado had she had assistance in identifying and securing care for her mother.

A much needed service would be assisting people in creating a long term care plan that outlines how they want to be cared for in their later years (Stolee, Zaza & Starratt, 2014). Developing a long term care plan is actually on par with planning for one's retirement and as such should be in place by the time one reaches their mid-50s to early 60s (before retirement). Because support services are primarily focused on functional decline, this planning service

should also give attention to creating a long term care plan from a holistic perspective. A well thought out advance plan should include support for functional decline but also identification of preferred routines, cultural values, areas of interest, social connections and spiritual fulfillment (Iecovich, 2008; Kane, 2001). Even though the data used for this paper was focused on an adult child stepping into the role as primary care giver in reaction to their parents' "unexpected" failing health (Lévesque, et al., 2010), spouses, other relatives and even friends fill the role of informal caregiver. For all who fill this role, making life-impacting decisions should not be done in crisis mode (Sims-Gould, et al., 2005).

Limitations of Paper

Due to the small numbers of caregivers interviewed and the limited number of adult children who visited the Resource Center within an eight month window, the data collected for this paper offers a preliminary picture of the multiple factors that contribute to barriers and utilization of services by informal care providers. Furthermore, the data collected from informal care providers only represents daughters and their mothers and does not represent how spousal relationships, daughters to fathers, sons to mothers or sons to fathers might differ in these roles (Ingersoll-Dayton & Raschick, 2004). In addition, because the relationship between the caregiver and care recipient is dynamic and intertwined, the data in this paper are a reflection of only one side of the experience (the care provider's). As the oral interviews support, the views and attitudes of care recipient play a key role in the selection and utilization of support services.

Future Studies

There are several future studies that could offer a deeper understanding of how the caregiver / care recipient dyad influences selection and utilization of services. For example, it could be valuable to understand how the existence of a mental health disorder influences the

dynamics between the informal care provider and the care recipient. It could also be valuable to understand how the changing roles between the adult child (informal caregiver) and parent (care recipient) influence the care recipient's willingness to accept the needed care for their increasing dependence without compromising their autonomy and sense of self (Ingersoll-Dayton & Raschick, 2004; Pipher, 1999, p.138).

CONCLUSION

The intent of this paper was to assimilate information on how care providers learn about available resources, identify usage and barriers to utilization of services; and how the care providers' needs are being supported. The opportunity to speak directly with caregivers about their experiences of caring for an aging parent made the emotional, social, and pragmatic challenges of the role very clear. Their stories emphasized that service utilization is relative to the personal values of the care recipient, perceived benefit of the services and geographic location; all of which support that service utilization is a very personal choice (Firbank, 2010).

A key lesson learned from this paper was the importance for the elderly and their care providers to receive needed support without having to spend countless hours searching for services or failing to discover that support is available. This information should offer insight for long-term care services and support providers to work toward bettering organizing and coordinating their efforts on behalf of their target audiences and in developing more effective outreach materials.

In conclusion, the role of the informal caregiver and their relationship to the care recipient is dynamic. The competing demands for time, effort and understanding of services against the constantly changing needs of the care recipient place the informal, primary caregiver in the position of having to continually identify, select and utilize services. These services are not always evident or easy to obtain. As Castora-Binkley et al. (2010) argue the utilization of support services for home care is a critical determinant as to whether or not the care recipient can remain at home. In the wake of this demanding effort, many informal care providers and care recipients are unnecessarily confused and grossly underserved.

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APPENDIX A. INVITATION TO PARTICIPATE

NDSU North Dakota State University

Department of Human Development and Family Sciences
NDSU Dept. 2615
PO Box 6050
Fargo, ND 58108-6050
701.231.8268

Title of Research Study: Caregiver Stress: First Person Accounts of the Perception and Utilization of Support Services

INFORMATION SHEET FOR INFORMED CONSENT

Greetings! I am a graduate student in a gerontology master's degree distance learning program that is administered through North Dakota State University. I am presently conducting a research project to assess the effectiveness of support services for informal caregivers who are currently or have recently cared for someone aged 65 years and above with a life-limiting illness for at least 3 months. My thesis will be a collage of the personal stories collected.

The purpose of this study will be to provide insight into:

- The types of support services caregivers utilize versus those available
- Factors that prevent available services from being utilized
- Possible gaps in support services that are offered

This information can be utilized by organizations and agencies offering support services to caregivers as well as the foundation for future research efforts.

Research Procedures

Because of your current/recent experience as an informal caregiver for someone 65 and over, you have been invited to participate in this study. Your participation will involve completing a written survey with questions about demographics (age, education, etc.) and the nature of your caregiving duties. You will also be asked to complete a more in-depth interview either in person or over the phone. I will ask you questions about your caregiving experiences and record your answers. This interview is expected to take about one hour, but could be longer or shorter.

Voluntary Participation

Participation in this study is entirely your choice. You may change your mind and withdraw from the study at any time without penalty. You are free to skip any questions you find uncomfortable. If you choose to withdraw from the study, we will not use any data we may have collected from you.

Benefits and Risks

By taking part in this research, you will be able to share and reflect upon your experiences as a caregiver. Many people find the survey questions interesting. In general, the information you

provide will help organizations and agencies offer better support services to caregivers, as well as provide a foundation for future research efforts. However, you may not personally receive any benefits from contributing to the study. Participation in this study contains no known risks other than what you would encounter in everyday life.

Confidentiality

All of the responses that you give will be kept confidential. To ensure your privacy, you will be assigned a subject number, and your name will not be on any of your answers. The information you share will be compiled into an ethnographic style (i.e. personal history) document with your experiences being combined with those of other participants. You will not be individually identified in this document.

For Questions or Concerns:

If at any time you have questions or concerns about this study or your participation in it, you may contact any one of the following:

Me – Debbie Shapiro:

- 925-330-0225 (cell)
- debra.shapiro@my.ndsu.edu
- 7828 South Hill Circle, Littleton, CO 80120

My Faculty Advisor

- Melissa Lunsman O'Connor
- Assistant Professor
- Department of Human Development and Family Science North Dakota State University
- 1310 Centennial Blvd., EML Hall 283D
- PO Box 6050
- Fargo, ND 58102
- Phone: (701) 231-8268
- Melissa.oconnor@ndsu.edu

NDSU at:

Department of Human Development and Family Sciences
NDSU Dept 4000
PO Box 6050
Fargo, ND 58108-6050
Phone: (701) 231-8268

If you have questions about your rights or complaints about this research, you may contact the NDSU Human Research Protection Program at 701.231.8908, toll-free at 1-855-800-6717, by email at ndsu.irb@ndsu.edu, or by mail at: NDSU HRPP Office, NDSU Dept. 4000, P.O. Box 6050, Fargo, ND 58108-6050.

You are freely making a decision whether to be in this research study. Completing the written survey means you have understood this information and have chosen to participate.

Thank you in advance for taking part in this research. If you wish to receive a copy of the final document, please send your request to me by email to debra.shapiro@my.ndsu.edu

Best regards,
Debbie Shapiro

APPENDIX B. INFORMED CONSENT

Dear friends,

I am starting the process of gathering data for my Master's Paper in Gerontology. One of my key goals for enrolling in this program was to find better means for supporting family members, friends, and neighbors who currently provide or have provided substantial care to someone aged 65 years and above with a life-limiting illness. My paper will discuss the experiences and needs of such caregivers, and I am looking for volunteers who are willing to share their stories.

The criteria for participating are as follows:

1. Participants should currently be caring for someone aged 65 years and above with a life-limiting illness, OR previously acted as a caregiver for such a person within the past five years.
2. Participants should have provided care for at least 3 months on an informal basis, meaning not as part of a paid professional job.
3. The care recipient can be living (or have lived) in one of the following settings while receiving care: a) their own home, b) the participant's home, or c) a long-term care facility, as long as the participant is/was assigned Power of Attorney or guardianship.

Participation will involve completing a written survey, then taking part in an interview with me. I will send the survey by e-mail (or postal mail if preferred) for you to complete at your convenience.

The interview will be done either in-person or over the phone, depending upon geographic restrictions. This interview could take up to one hour. Out of courtesy to your time, this will be scheduled at your convenience after you have returned the survey.

I will compile all the responses to the survey and interviews into a narrative that can be used by researchers and community leaders to help caregivers get the services they need. Participation is completely voluntary and confidential. Individual names will not be mentioned in my paper, and your experiences will be written about in combination with others. And of course, I would be happy to share my final findings for those who indicate interest.

If you meet the criteria and are interested in participating, please either email me at debra.shapiro@my.ndsu.edu or call by phone 925-330-0225. Upon confirmation of your interest, I will send you more information about the study, along with the written survey.

I would appreciate your sharing my request for volunteer participants with your neighbors, friends or relatives who meets my caregiver criteria and who you think might be willing share their experiences as caregivers.

Thank you in advance for your assistance.

Best regards,
Debbie Shapiro

APPENDIX C. WRITTEN QUESTIONNAIRE

Caregiver Stress: First Person Accounts of Perspective and Attitudes toward Support Services

If you complete this survey, that will be taken to mean you have read the information sheet about the study and voluntarily consent to participate. Please return the completed survey by (DATE). You may attach and e-mail your survey to Debbie Shapiro at debra.shapiro@ndsu.edu mail a hard copy to:
7828 South Hill Circle, Littleton. CO 80120.

Subject number: _____

Demographic Data of Caregivers

Please indicate your age range:

- 25-35
- 36-45
- 46-55
- 56-65
- 66-75
- 76-85

Please indicate your highest level of education:

- High School Diploma
- Some College
- Associate Degree
- Bachelor of Arts/Science
- Masters' Degree
- Doctorate
- Other _____

Please indicate your total annual income level while acting as a primary caregiver:

- \$25,000 - \$35,000
- \$36,000 - \$55,000
- \$56,000 - \$75,000
- \$76,000 - \$95,000
- \$96,000 - \$125,000
- \$125,000 - \$250,000
- Over \$250,000

Please provide your five digit zip code:

Subject number: _____

Demographic Data of Person Under Care

(Questionnaire to be given to each participant along with the Informed Consent)

Please indicate the age range of the person under your care:

- 25-35
- 36-45
- 46-55
- 56-65
- 66-75
- 76-85

Please indicate the highest level of education of the person under your care:

- High School Diploma
- Some College
- Associate Degree
- Bachelor of Arts/Science
- Masters' Degree
- Doctorate
- Other _____

Please indicate the total annual income level of the person under your care:

- \$25,000 - \$35,000
- \$36,000 - \$55,000
- \$56,000 - \$75,000
- \$76,000 - \$95,000
- \$96,000 - \$125,000
- \$125,000 - \$250,000
- Over \$250,000

Please provide the five digit zip code of the person under your care:

Summary of Person in Care

Please describe the relationship between you and the person in your care.

How long have you been in this relationship?

What is/was their primary illness?

What if any additional illnesses or diseases do/did they have?

Did they live with you or in their own home or somewhere else? If the person under your care lived somewhere else, where did they live?

If the person in your care lives in their own home or somewhere else, how far away do you have to travel to care for them?

Primary Caregiver Experience of being the Care Provider

How did you come to be the primary caregiver?

How many hours per week do/did you provide care?

Tell me about the kinds of assistance you provide(d) to this person.
(time, financial, emotional, physical)

Tell me about how the person in your care responds/responded to your assistance?

How many other people lived in your home with you?
Relationships and Ages?

How many people lived with the person under your care?
Relationships and Ages

APPENDIX D. ORAL INTERVIEW QUESTIONNAIRE

The following questions will be asked of study participants during the as part of the oral interview.

Caregiver Support Systems (Informal Care Team) for the Person In Care

1. Did any other informal person assist in providing care?
2. *Relationship (sibling, spouse, neighbor, community member)*
3. What contributions did your family/house members make in cooking, cleaning, grocery shopping, laundry, yard work or home repairs, errands or providing financial assistance?
4. Can you please provide an average of either hours/dollars per week/month?
5. Can you describe or rate the strength of your care team as well as the weaknesses?
6. What do you think would have made your care team better?

Utilization of Assistance and Direct Support Services – for person in care

1. What community, agency support services, if any, did you utilize for the person under your care?

For each service used:

2. How long did you use this service? Was there a related cost?
3. What factors contributed to your selecting this service?
4. What about this service was helpful?
5. What about this service could have been improved?
6. Was the service located in the community where you resided or where the person in your care resided?
7. Which, if any, support services you were aware of and elected not to use?
8. How long did you utilize these services? Was there a related cost? What amount of travel time was required to get the person in your care to/from this service? If the service was home based, how many hours per day/week as this service used?
9. Can you explain to me any factors that contributed to you deciding not to use these services (distance, hours of service, costs, reputation of service)?

10. Which of the services you are using or have used would you recommend to someone else?
11. Did you feel that the kinds of services of available (whether you used them or not) fully addressed the needs of your loved one?
12. What other types of support services do you think would be/have been helpful to you?
13. What is/was your preferred method for learning about available support resources?
 - Internet
 - Word of Mouth
 - Drive by/ walk by
 - Medical Personnel
 - Religious Leader
 - Community Resource Center
 - Type(s): _____
 - Newspaper
 - Radio/TV
 - Other

Please rank your top 5 preferred resources in order of preference with 1 as the highest preference and 5 as the lowest.

- ___ Internet
- ___ Word of Mouth
- ___ Drive by/ walk by
- ___ Medical Personnel
- ___ Religious Leader
- ___ Community Resource Center
- ___ Newspaper
- ___ Radio/TV
- ___ Other

Caregiver Caring for Own Needs

1. Describe any training or education you completed regarding the nature of the illness of the person under your care and how to best care for that person.
2. If you completed such training/education, explain how it helped you in your role as a care provider.
3. In what ways did you find time to care for yourself (support group, engagement in activities of interest, exercise, time away with friends/family, exercise, meditative – yoga, tai chi, etc.)?
4. How often were you able to participate in these activities?
5. If you elected to use support services can you please share why you choose these?

6. Were there other support services you were aware of and elected not to use?
7. Which ones?
8. Can you explain to me any factors that contributed to you deciding not to use these services (distance, hours of service, costs, reputation of service)?
9. Was your own primary physician aware of your role as a caregiver? If so, did he/she or a member of their office ever direct you to support services? If yes, can you please provide details?
10. If there were a resource/respice site near where you lived that offered classes and opportunities for you to restore yourself (mentally, physically emotionally) would you use this service?
11. How frequently?
12. If financial resources were not an issue, would you pay for these respice services?
13. Did you feel that the kinds of services of available (whether you used them or not) fully addressed your needs?
14. How did you learn about the services you utilized for yourself?

- Internet
- Word of Mouth
- Drive by/ walk by
- Medical Personnel
- Religious Leader
- Community Resource Center

Type(s): _____

- Newspaper
- Radio/TV
- Other

Please rank your top 5 preferred resources in order of preference with 1 as the highest preference and 5 as the lowest.

- ___ Internet
- ___ Word of Mouth
- ___ Drive by/ walk by
- ___ Medical Personnel
- ___ Religious Leader
- ___ Community Resource Center
- ___ Newspaper
- ___ Radio/TV
- ___ Other

15. Do you have additional thoughts you would like to share regarding your experiences of caring for another person?

Thank you for your participation in this study and for sharing your time and experiences.

APPENDIX E. RESOURCE CENTER AGENCY SURVEY

Resource Center – Agency Survey

Date of Survey #2 _____

Contact method: ___ Phone ___ Email ___ In Person

On a scale of 1 to 5 with 1 being low and 5 being high:

Were you able to connect with the resources provided? ___ Yes ___ NO

If yes, which services? _____

The referral agency staff was courteous

1 2 3 4 5

The referral agency staff listened to me needs

1 2 3 4 5

The referral agency staff was able to assist me

1 2 3 4 5

The Aging Well Resource Center was helpful in connecting me to needed resources

1 2 3 4 5

Office Use Only
Status of Survey 2
___ Completed
___ In progress / another follow up call needed
___ In progress but no additional follow up needed
Updated in Zoho _____ / Date _____