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Walden University

College of Social and Behavioral Sciences

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Cynthia J. Uecker

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Walden University
2020

Abstract

Work Adjustment and Family Caregiver Engagement in the Healthcare Transaction

by

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MBA, Upper Iowa University

BS, Upper Iowa University

Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Philosophy

Organizational Psychology

Walden University

November 2020

Abstract

Unpaid family caregivers in the U.S. now exceed 40 million people, and the question of how to effectively support the family caregiver is now decades old. Healthcare's dominant perspective is reasonable because healthcare sees the family caregiver in the healthcare transaction. The research consistently reports caregivers cite lack of information and training as a primary reason for feeling the healthcare provider is non-supportive. This qualitative phenomenological study employed semi-structured interviews to explore whether non-supportive might represent a disconnect between caregiver and the healthcare provider purposes with respect to the caregiver role. The theory of work adjustment provides context for considering the caregiver role as a work role, and the potentially efficacious effect of that on improving communication in the healthcare transaction. A purposeful sample of 9 participants was recruited from caregiver support groups and the snowball method. Manual coding and NVivo were used to develop codes and themes, and analyze the data. Findings affirm unpreparedness for the caregiver role while also evidencing active and organized responses to caregiving role challenges. In an emergent sense, participants first struggled with conceptualizing their roles in work terms but gradually gained confidence and began applying some terms to their experience, ultimately freely articulating dynamics of their roles in work terms. This suggests a communicative context that might improve supportive healthcare interactions, strengthen understanding between healthcare providers and the essential family caregiver, and affect positive social change. Healthcare providers can contribute substantially to reducing the early confusion of caregiving with a handout directing caregivers to the now substantial authoritative information for caregivers on the Internet.

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Chapter 1: Introduction to the Study

The family caregiver has become a favorite topic of research, particularly in gerontology and nursing, as interest grows in the phenomena of the caregiver journey. There is interest in understanding the triumphs and stressors associated with caregiving, developing ways to decrease caregiver burden, and helping the caregivers in their roles within the healthcare transaction. For the most part, the research has explored the caregiver burden alongside reasons for assuming the caregiver role, and in some cases, the positive effects reported by caregivers. The challenge of any intervention is to understand the caregiver or risk failing to meet the caregiver's needs. This research explores the caregiver in the role of a worker as understood utilizing the work adjustment theory (TWA) and various topics that contribute to understanding work adjustment. This chapter provides a background of the concept of the caregiver role and an overview of the study, its theoretical framework, research questions, operational definitions, assumptions, scope and delimitations, limitations, and significance.

Background of the Problem

The family caregiver is an intricate role in which individuals adjust from traditional family roles in pursuit of goals for caring for family members, assuming responsibility for new tasks both in caregiving (Elliott, Shewchuk & Richards, 2001) and in interacting with the family member's healthcare providers (Montgomery & Kosloski, 2009). Caregivers report frustration with non-supportive and ambiguous interaction with healthcare workers (Neufeld, Harrison, Stewart & Hughes, 2008; Neufeld & Eastlick Kushner, 2009).

There is considerable interest in providing support to the family caregiver (Levesque et al., 2010; Montgomery & Kosloski, 2009). In the United States, the family caregiver (also called an informal caregiver) is the primary giver of long-term care to aging and chronically ill or disabled family members (Montgomery & Kosloski, 2009). Every caregiving situation is unique regarding the situation and the tasks caregivers perform (Montgomery & Kosloski, 2009). Each caregiver's reason for assuming the caregiving role and expectation of that role are also different (Montgomery & Kosloski, 2009). Finally, the family caregiver role is not an independently occurring phenomenon, but an extension of an existing role in a family relationship, and as such, the caregiver experience can be meaningful (Montgomery & Kosloski, 2009).

Healthcare providers credit the family caregiver as essential, sometimes referring to the family caregiver as the “hidden” healthcare workforce (Lichtenberg et al., 2009). Nevertheless, caregivers feel unsupported and report negative experiences in the healthcare transaction (Neufeld et al., 2008; Neufeld & Eastlick Kushner, 2009). Current research into caregiver dynamics has focused on caregiver burden and associated stress (Pinquart & Sorensen, 2003; Carbonneau, Caron, Desrosiers, 2010) and adverse outcomes (Semiatin and O’Connor, 2012). Despite the considerable stress of family caregiving, some caregivers who report a positive experience also report less stress in the caregiving role (Pinquart &, Sorensen, 2003, Semiatin and O’Connor, 2012), reduced depression, and lower level of burden. The literature primarily discusses the caregiver as someone whom healthcare providers must also care for, some calling the caregiver the second patient (Reinhard et al., 2008). However, caregivers may think of themselves as

fulfilling a role that is more like a job with familial responsibility than as someone needing healthcare intervention or medical attention. This research explores the knowledge gap in the literature by examining the caregiver role in the healthcare transaction from the perspective of work adjustment.

There are immediate implications associated with this gap. It is unfair to treat the caregiver, who approaches the healthcare transaction with the expectation of participating with other experts in the care of his family member, like a patient. Caregivers do not have a contract with healthcare providers, and thus, no legitimized role even though healthcare recognizes the importance and significance of caregiver input. There may also be some boundary violation by healthcare providers if taking care of the caregiver involves queries of a personal nature. Perhaps most significant from a work adjustment perspective is the effect on caregivers if they approach the healthcare interaction expecting to be treated as members of the healthcare team, and instead, the healthcare provider chooses to doctor the caregiver and treat them as another patient.

With this gap in mind, this qualitative study examined caregiver reports of non-supportive interaction with healthcare workers (Neufeld et al., 2008; Neufeld & Eastlick Kushner, 2009) for evidence that non-supportive interaction might be the result of a disconnect between purposes of healthcare and the caregiver. Narrative interviews with family caregivers explored the participant's experience in the healthcare transaction and with healthcare providers. Interview questions were developed from broad categories exploring the participants' feelings about becoming a caregiver, the healthcare interaction, and support. Data collected from these interviews were analyzed for recurrent

themes thought to be indicators of evidence that a work framework might facilitate a more positive family caregiver experience.

Chapter 1 provides background information for the commonly discussed caregiver role and elements that contribute to caregiver burden, along with an overview of the research question, the purpose of the study, the theoretical framework, the limitations of the study, and the social change implications.

Problem Statement

The central question for this study is, “Why do family caregivers report non-supportive interaction in the healthcare transaction?” This study explores this question with a narrative method using semi-directed in-depth interviews with individuals who have primary caregiver roles with an aging or disabled family member.

We know that work satisfaction is related to job performance, and job performance links to hiring employees deemed a good fit for the organization (Dawis & Lofquist, 1984). Work satisfaction is also a dynamic of individual self-efficacy and the individual’s perception of the ability to perform successfully (Esmaeili & Hashim, 2014). The ongoing satisfactoriness of this relationship depends on the ability of the organization and the individual to adjust to change in the others’ needs (Dawis & Lofquist, 1984). Individuals modify and refine their responses to the organizational environment, and organizations provide training specific to changes in employee skill demands (Eggerth, 2008).

The literature does not provide a clear definition of the caregiver in the healthcare triad. With the caregiver role undefined in the healthcare transaction, the otherwise

utilitarian process of work adjustment breaks down. Considerable research describes the caregiver role, the caregiver's associated burden, and the positive aspects of caregiving that mitigate caregiver burden. In large part, the healthcare industry approach to the caregiver is to view him or her as a patient or someone in need of a healthcare intervention. No research has examined this phenomenon from the view that the caregiving role is a work role.

Purpose of the Study

In previous studies (Neufeld, Harrison, Stewart & Hughes, 2008; Neufeld & Eastlick Kushner, 2009), caregivers have reported non-supportive interaction in the healthcare transaction. Women caregivers described threats to credibility, ineffective assistance, and failed expectations of support that fostered negative feelings (Neufeld, Harrison, Stewart & Hughes, 2008). In a study of male caregivers, Neufeld & Eastlick Kushner (2009) found indicators of non-supportive interaction with healthcare among men was chiefly a failure to provide information that enabled orientation to the caregiver role and decision making, details about their family members' conditions, and assistance with accessing useful resources

The purpose of this study was to explore whether caregiver expectations and responses in the healthcare interaction are more typical of a person in a work setting than one who is a subject of a healthcare intervention. In a broad sense, the research method represents established epistemological and ontological assumptions around which researchers build an understanding of phenomena (Maxwell, 2005). The qualitative study utilizes multiple paradigms with specific method strategies related to these underlying

assumptions (Maxwell, 2005). This study uses the social constructivism paradigm. In the social constructivism paradigm, individuals strive to understand their environment, developing an understanding of their experience (Creswell, 2007). The individual's explanation of his experience with a particular phenomenon reveals complex meaning and contexts that may generate theory about the phenomenon (Creswell, 2007).

Research Questions

This study intends to contribute to the understanding of the family caregiver in the healthcare transaction from a work adjustment perspective. The central research question is, “Why do family caregivers report non-supportive interaction in the healthcare transaction?” Additional research questions form the basis of the semi-structured interview. First, how much control does the caregiver have in the healthcare transaction? Second, do caregivers feel healthcare values their participation in the healthcare transaction? Last, do caregivers view the healthcare provider as providing leadership?

Theoretical Framework

The theoretical framework of this research describes the interaction between organizations and individuals in work correspondence. Such a framework helps conceptualize the caregiver role as synonymous with a work role, which might help healthcare and the caregiver find common ground in their interaction with each other. As such, better and more appropriate responses to caregiver needs can decrease caregiver dissatisfaction in the healthcare exchange.

TWA holds that work is a process in which the individual worker and the work environment interact in reciprocal ways for the benefit of both (Dawis & Lofquist, 1984;

Eggerth, 2008). The organization considers a worker satisfactory when he satisfies the labor requirements of the work environment (Dawis & Lofquist, 1984; Eggerth, 2008). The work environment is deemed satisfactory by the worker when the worker experiences met needs, and correspondingly, this worker is satisfied (Dawis & Lofquist, 1984).

In psychology, we think of individuals as organisms responding to an environment in potentially many ways and under many different conditions (Dawis & Lofquist, 1984). These conditions, commonly known as stimulus conditions, evoke active or reactive responses (Dawis & Lofquist, 1984). This response repertoire is the basis for all future responses, evolving and becoming more sophisticated, and used by the individual to understand the environment and communicate with the environment (Dawis & Lofquist, 1984). Eventually, the individual can report on his experience with the environment using his developing response repertoire (Dawis & Lofquist, 1984). Because individual memory is unique, perceptions of the stimulus condition(s) and response(s) to them are also unique and may not agree with those of other individuals (Dawis & Lofquist, 1984).

Other individuals may observe another's response(s) to a particular stimulus condition and infer aspects of that person's experience, allowing an independent view of the observed person's repertoire of responses (Dawis & Lofquist, 1984). Reports on phenomena by observers are as unique as the reports of the individual under observation, and they may not agree (Dawis & Lofquist, 1984). Further, if there is more than one observer, each observer's report is subject to variance due to his unique memory and the

influence of the observer's personal experience (Dawis & Lofquist, 1984). The development of observation standards reduces the subjectivity of observer reports and produces more reliable observations (Dawis & Lofquist, 1984). Otherwise, social norms dictate standards of behavior by which we define acceptable behavior (Dawis & Lofquist, 1984). In the context of these social norms, institutions form to regulate behavior and influence individual development (Dawis & Lofquist, 1984).

We can define an individual's skills as responses, which recur over time in an iterative sense, subject to modification and refinement (Dawis & Lofquist, 1984). While each has a unique skill set, some commonalities will exist across individuals, and these commonalities allow us to define a skill dimension from which it is possible to rank skill performance (Dawis & Lofquist, 1984). Characteristics of a skill dimension describe difficulty, economy of effort, and efficiency (Dawis & Lofquist, 1984). For the sake of economy and efficiency, we further analyze these many skills using their commonalities to identify central dimensions called ability dimensions (Dawis & Lofquist, 1984).

Within the TWA framework are two models. The predictive model predicts outcomes of the match between the individual and the work environment, and the interaction model describes how the individual and the work environment adjust in their interaction (Dawis & Lofquist, 1984, Eggerth, 2008). The predictive model assumes that individuals act in ways that enable the fulfillment of their needs and the needs of the environment (Dawis & Lofquist, 1984; Eggerth, 2008). The work environment reinforces such behavior with an end that the satisfaction of the worker and the environment is equal (Dawis & Lofquist, 1984; Eggerth, 2008). However, because individuals and work

environments are not equal, a satisfied worker may not be satisfactory in the organization's view and vice versa (Dawis & Lofquist, 1984; Eggerth, 2008).

TWA assumes that people want correspondence in the work environment and wish to sustain it (Eggerth, 2008). The TWA interaction model describes the effort to achieve and maintain correspondence in a work adjustment process as a continuous one of worker and organizational effort to meet the needs of the changing work environment (Dawis & Lofquist, 1984, Eggerth, 2008). Changes in the work environment may be external to the worker, arising from mergers, for example, or internal as with job redesign (Eggerth, 2008). Adjustment to work is a continuous process that includes analysis of employee personality and adjustment styles and their relationship to the style of the work environment (Dawis & Lofquist, 1984). Such information helps organizations estimate how workers and the environment will respond in the adjustment process of desired correspondence (Dawis & Lofquist, 1984). Work environment redesign usually stems from changes in technology and the development of new products. With the desire to retain the current workforce as much as possible, organizations identify skills needed for tasks required to meet the goals of a new design (Dawis & Lofquist, 1984). The organization then determines the desired reinforcers of the preferred workforce and designs a reinforcer system that will satisfy the majority of those workers (Dawis & Lofquist, 1984). Workers can drive their internal changes when seeking an opportunity to advance within the organization or to change/improve work/life (Eggerth, 2008).

Nature of the Study

This study used a qualitative design and semi-structured interview questions to explore how caregivers conceptualize their caregiving roles and whether it is anything like work. Of interest was whether the caregiver work experience can explain the dynamics of the caregiver role and caregiver interaction in the healthcare transaction and how the caregiver develops responses to both. Participants consisted of adult caregivers of parents or significant others. Questions gleaned from the research questions attempted to generate participants' perspectives and experience with phenomena that eventually will serve to decrease the gap in the literature on the topic. The advantage of semi-structured interview questions is that they can be pre-formulated, allow participants to communicate their responses freely, produce reliable data, and contribute to the generalizability of the results (Maxwell, 2005).

Operational Definitions

The family caregiver: In this paper, the term family caregiver refers to an individual who provides unpaid care for a sick, disabled, or elderly family member at home. A caregiver can be anyone with a personal relationship with the care recipient, committed to assisting the care recipient (Blum & Sherman, 2010).

The family caregiver role: Family members assume a caregiver role when a family member has health-related needs. Like a new job, caregiving requires shifts in previous roles, learning new skills, and demanding challenges (Net of Care, 2011). Some family caregiver tasks include personal care, transportation, coordination of medical visits, and daily household activities, including cleaning and shopping. Caregivers may

also manage finances, coordinate medical care including dispensing of medication, and perform medical treatments, communicate with the medical team, provide companionship and emotional support, and coordinate services (Net of Care, 2001). In essence, the family caregiver needs to define his or her new role in these terms and learn practical ways to manage its various aspects.

Dyad/Triad: The relationship between a patient and a healthcare professional is a dyad. The advent of a family caregiver in the relationship changes it to a triad consisting of the healthcare professional, the family member/patient, and the family caregiver.

The healthcare transaction: The interaction between the family member/caregiver dyad and the healthcare professional(s).

Non-supportive interaction: The non-supportive interaction is a relationship with family, friends, a healthcare organization, and healthcare professionals that the caregiver views negatively for not having provided the expected support.

Assumptions

One assumption was that participants had some experience with work environments, possessed an understanding of work responses and work behavior, and had some ability to conceptualize their adjustment to workplace challenges. Another assumption was that participants were older as most of their family members are elderly. This age factor contributes indirectly to the expectation that participants possessed experience with work adjustment.

Scope and Delimitation

There was no demographics limitation by gender, income, or education.

Participants were adults caring for an aging family member. The research population was delimited only by the availability of participants in my geographical area, with results expected to be transferable to individuals outside the selected geographical area.

Limitations

This study used a purposive sample, guided by recommendations for qualitative research to visualize the magnitude of information a sample might produce (Creswell, 2007), which may decrease the generalizability of the results. To control the sample size, selection criteria to limit participant eligibility to caregivers of spouses or aging parents provided some control of sample size. The selection criteria are also convenient, which increases the likelihood participants would be at least middle-aged and have work experience, but at the same time, decreases the inclusion of participants with less or no work experience. Accessing elite stakeholders (Bakkalbasioglu, 2020), which in this case was the hospital and parent organizations, such as the hospice network, and other local agencies, were obstacles in early recruiting activity and may have some import to the generalizability of this study. Recruitment of the final sample of participants was primarily from support groups and by word of mouth, leaving some question if the sample used is representative of the entire population.

Social Change Significance

The research on the family caregiver has contributed enormously to understanding issues caregivers encounter and the caregiver burden, including the stress associated with

carrying out their obligations. It does not explore the caregiver in a work role, however, and the current view may not fully explain the problem of a caregiver feeling unsupported in the healthcare transaction. It is possible that at the onset, caregivers have a different view of their role than the one healthcare assigns to them, and with that, a different expectation about how the interaction with their family members' healthcare providers should go. The healthcare goal to treat the person may be at odds with a caregiver's objective of finding assistance with the caregiver role, and these different purposes could contribute to caregiver stress and burden. This research has the potential to provide a perspective that will narrow the gap in the literature, add understanding to the existing literature, understand the caregiver better, and identify additional ways to facilitate the caregiver role. Such information will help establish a more realistic definition of the caregiver, increase awareness among healthcare workers to improve communication with caregivers, and perhaps encourage a protocol for integrating the caregiver role into the healthcare environment in which he or she must work.

Summary

The experience of the family caregiver with the healthcare system is crucial and necessary to understand if we are to support the caregiver role fully. Research exploring the caregiver role and challenges, obstacles, and stress caregivers face in accomplishing their purposes is substantial. However, the caregiver role remains mostly undefined in the healthcare system regarding ways healthcare manages the caregiver in the healthcare transaction. Caregivers are not patients; neither are they employed by the healthcare system.

In the interest of understanding better how the caregiver perceives himself in his role in the healthcare transaction, this qualitative study proposes to explore caregiver perceptions of their experience with work-related adjustment dynamics. This chapter introduced the problem of interest and discussed the rationale for the study and its theoretical construct. This chapter also reviewed what we know about the caregiver and what we do not know.

Chapter 2 provides a review of existing literature on the topic, along with the literature search strategy. Chapter 3 describes the study methodology, the interview questions, and the demographics of the study participants.

Chapter 2: Literature Review

Introduction

The family member who becomes a caregiver to an aging parent assumes a role that originates in and evolves from the family culture. The caregiver role requires adjustment, not only to changes in the family member's health but to added responsibility to meet the family member's needs. The literature indicates healthcare focuses its intervention on relieving the caregiver burden (Reinhard et al., 2008), defining it as stress associated with the caregiver role (Pinquart & Sorensen, 2003; Carbonneau, Caron, Desrosiers, 2010). However, there is nothing in the literature addressing the value of the caregiver's work experience in the adjustment process. There are aspects of the caregiver adjustment to the caregiver role that we can understand from a work adjustment perspective that may not only facilitate understanding of the caregiving process but also be more responsive to the role of the caregiver.

Evidence of the caregiver burden phenomena dates back more than three decades in the literature (Brown & Brown, 2014). This literature review begins with statistics illustrating the relationship of larger populations of aging individuals and the rise of caregivers in the U.S., followed by a discussion of the caregiver role. Next, the discussion focuses on psychological theory beginning with social cognition, which argues for the schemas all individuals develop over time and utilize to make sense of their environments. Subtopics of this category include social power and the leadership prototype. Next is a discussion of attribution theory with subtopics of bias and learned helplessness followed by a discussion of self-efficacy and the positive experience.

Finally, is a section on the caregiver career highlighting the burden phenomenon followed by a discussion of the healthcare transaction that includes elements of boundaries, disengagement, and caregiver adjustment to change.

Literature Search Strategy

When I discovered the topic of caregivers, I was one myself. Two articles reporting non-supportive interactions by male and female caregivers moved me to explore further. The focus of the literature to date has been on viewing assistance for caregivers from a burden perspective without much attention to the dynamics of somewhat at work in a work role. This study used TWA and its various and complex elements, as a framework for understanding the caregiver role and the caregiver's adjustment to that role. The literature search was organized around broad categories of caregiver, caregiver and healthcare, job/work, organization, and psychology. For caregiver and healthcare, subcategories include patient, caregiver role and burden, caregiver and provider, healthcare contracts, independent worker. In the job/work category subcategories include vocational psychology, TWA, and self-employment/independent contractor. The job/work and organization categories overlapped somewhat but were retained as separate to explore boundaries, caregiver career, change, customer service, disengagement, and leadership in the organization category. In the psychology category, subcategories developed for normative processes such as social cognition, attribution theory, learned helplessness, self-efficacy, and positive psychology related to work adjustment.

The literature search took place primarily in the Walden University online library using primary databases Academic Search Complete, Business Source Complete, PsycARTICLES, Sage Premier, Medline, Science Direct, and others and various eBook options such as EBSCO eBooks and PsycBOOKS. I also used the Internet for general topic searches about the most current non-peer-reviewed information to trigger further research in the Walden Library databases. Sites such as Administration on Aging, American Psychological Association, Centers for Disease Control (CDC), the U.S. Department of Health & Human Services (HHS), and the United States Census were valuable for acquiring the most current statistics and evolving legislation. Caregiver and caregiving websites such as the National Alliance for Caregiving publish statistics as well as current perspectives and experiences of caregivers. I also read articles in newspapers and magazines and attended one nursing seminar to gain insight into the nursing customer service perspective. *Palliative Medicine, Hospice & Palliative Medicine, Qualitative Health Research, The Family Journal, Journal of Applied Gerontology, Journal of Family Nursing, Journal of Management, Palliative Medicine, and International Journal of Nursing Studies* were several journals that frequently appeared in search results. I read and cited from the *American Journal of Alzheimer's Disease and Other Dementias, Policy, Politics, & Nursing Practice, Nursing Ethics, Journal of Cross-Cultural Psychology, and Clinical Nursing*, among others. I referenced books authored by R.V. Dawis & L.H. Lofquist on TWA for work adjustment theory, and others for topics such as attitudes and opinions of workers revealed in the TWA literature.

Review of Literature

Historical Shifts

The US Census predicts the population of people aged 65 and over will double and make up 21% of the population by the year 2050, increasing from just over 43 million to almost 84 million (United States Census, 2014). Already the health care industry is experiencing growth in areas of home health care, care facilities, and community living (United States Census, 2014). In the past year, nearly 30 percent of Americans were caregivers of family members (APA, 2015).

Three factors contributing to the increase in populations of older adults include fertility declines, longer lifespan (Hilton, Koper-Frye & Krave, 2009), and the aging of baby-boomers (United States Census, 2014, Hilton, Koper-Frye & Krave, 2009). Fertility rates, which reflect the number of live births among women from 15 to 44 years of age, declined in the US from 3.5 in 1950 to 1.4 in 2003 (Hilton, Koper-Frye & Krave, 2009). Life span is increasing due to improvements in health screening and technology, as well as the end of epidemics (Hilton, Koper-Frye & Krave, 2009). Finally, baby boomers, which make up 26% of the U.S. population born from 1946 to 1964, are reaching retirement age (United States Census, 2014, Hilton, Koper-Frye & Krave, 2009).

In 2012, 36% of those over age 65 reported some disability including mobility, hearing, vision, ability to perform daily activities (ADLs), ability to prepare meals, etc., which may have been minor but required some assistance (Administration on Aging, 2013). Of these, approximately 3.7 million were receiving paid or unpaid assistance with

personal care, and an estimated 28.5% were unpaid with 18.9% caring for someone over the age of 50 (National Alliance for Caregiving & AARP, 2009).

Anticipating the effect of aging baby boomers, considerable interest developed in 1999 to contain costs of healthcare while ensuring quality of care and availability of services (Takamura, 1999). One outcome was the establishment of a National Family Caregiver Support Program in 2000 under the Older Americans Act Title IIIE, to administer grants to states and territories so they can fund assistance for informal caregivers and family caring for aging adults in their homes (Administration on Aging, 2013). In 2012, HHS created The Administration for Community Living (ACL) to work with grant recipients to ensure the effectiveness of programs providing support for older adults living in their homes (ACL, 2013). The ACL's most important role is to ensure programs reflect the interests of this diverse population of aging Americans, their families and caregivers, and those organizations that are key to sustaining their quality of life (ACL, 2013).

Although there may be many services, availability of services for aging populations in the US changes, and is characterized by growing demand, as people are healthier and live longer (Browdie, 2010; AOA, 2018). In addition, there is an increased need for services resulting from lower retirement incomes, and scarce funding for discretionary services (Browdie, 2010).

Funding is a complex phenomenon resulting from varying ways of funding at state and local levels, and leverages asserted in favor of constituents of politicians (Browdie, 2010). Among state funding sources are the lottery, property taxes, community

contributions, and Medicaid (Browdie, 2010). With the goal of optimizing services, focus is on the terms of managed care at delivery levels and managing services for chronic illness (Browdie, 2010).

Most significant at this time is the retirement of baby boomers that comprise 26% of the population, putting a strain on Medicare and other services including caregivers caring for family aged 80 or 90 years (Hilton, Kopera & Drave, 2009). Longer life spans resulting from better healthcare means someone born in 1950 can expect to live to age 83 on average, thirty more years than someone born in 1900 (AOA, 2018). In the U.S. nearly 79% of caregivers have full or part-time jobs, and almost 50% of them are over age 40, yet reports show organizations have reduced caregiver support in EAPs and work-life programs by ten percent (Snelling, 2011).

In Iowa, the AARP conducted a survey of registered voters aged 45 or over about the Caregiver Advise, Record, Enable (CARE) Act. The CARE Act, which proposes to assist unpaid family caregivers when their family member goes to the hospital and during discharge to home, was supported by 80% of participants (AARP, 2015). Under the CARE Act, hospitals will be required to record the name of the caregiver upon admission of a family member and engage with the caregiver, advise the caregiver of major decisions made in hospital, and provide instructions on medical tasks the caregiver will assume at home (AARP, 2015).

Of respondents, 95% favored requiring hospitals to demonstrate medical tasks to caregivers, 93% wanted hospitals to inform caregivers of major decisions, and 84% voted to require hospitals and care facilities to record caregiver information upon admission

(AARP, 2015). Training or instruction on medical tasks was considered extremely important or very important by 87% of participants (AARP, 2015). Further, half of the caregivers responding indicated they had not received live demonstrations of tasks they would perform after discharge. Activities performed by Iowa caregivers included transportation, shopping, housework, meal preparation, financial tasks, medication management, nursing tasks, and assisting with ADLs (AARP, 2015).

Of registered voters over the age 45, most have experienced some kind with unpaid caring for a family member, and half of those who have never provided care report the likelihood of providing unpaid care in the future (AARP, 2015). Most Iowans (68%) over age 45 report they would prefer to stay in their homes as life becomes more difficult (AARP, 2015). Almost half of those over 45 who reported having been caregivers or expecting to have a caregiver role in the future indicated services are very necessary to the goal of facilitating their family member's desire to stay in their homes (AARP, 2015). They also indicated the importance of improving resources and training for caregivers (AARP, 2015).

Iowa caregiver experience most frequent reports were for stress experienced in caregiving duties (60%), work life balance (53%), getting enough rest (49%), and getting enough exercise (45%) (AARP, 2015). They also indicated issues with diet, personal health, finances, and their ability to visit their doctors (AARP, 2015).

The Caregiver Role

The healthcare worker or provider is a member of a group of professionals that are usually part of a larger organization of professionals. Presumably, smaller groups and

cultures within the organization assume quality standards set by the organization. In the primary care setting, the consultation between physician and patient is the baseline for delivery of services (Cheraghi-Sohi et al., 2008). In this initial consultation, a physician attempts to establish the dialog for quality dimensions of technical and interpersonal care (Cheraghi-Sohi et al., 2008). The healthcare practitioner's methods for approaching the consultation mitigates levels of satisfaction experienced by different consumers which, in turn is influenced by the consumer's expectation of service (Cheraghi-Sohi et al., 2008).

A partnership process enables practitioners to understand the caregiver's perspective of the caregiving situation and to incorporate it with their own knowledge of ways to support the caregiver such as with recommending services (Levesque et al 2010). Conceptually, the partnership is one between experts, in which the caregivers identify and communicate needs and what they expect regarding services, and the healthcare provider utilizes knowledge of services to support the caregiver need (Levesque et al., 2010). The Family Caregiver Support Agreement (FCSA) tool (an adapted form of the Carers Outcome Agreement Tool used in Canada) is intended to promote congruence between caregiver and practitioner perceptions of need and ultimately, delivery of services more relevant to caregiver need (Levesque et al., 2010).

In the UK patients surveyed indicated quality of interpersonal interaction in the primary care relationship as one aspect of primary care quality that is important to them (Cheraghi-Sohi et al., 2008). Quality of the interaction depended on patients' ability to see a physician who knew them, whether the physician showed interest in their ideas and

inquired about social and emotional aspects of the patient's life, and whether the physician included the patient in decision-making (Cheraghi-Sohi et al., 2008).

The demands of caring for a family member can have an effect on mental and physical health of the caregiver (Funk, Stajduhar & Cloutier-Fisher, 2010). Supporting caregivers with services is part of an effort to reduce negative effects of the caregiver role by recognizing the caregiver as having an integral role in the healthcare/client relationship (Funk, Stajduhar & Cloutier-Fisher, 2010; Lévesque, Ducharme, Caron, Hanson, Magnusson, Nolan, & Nolan, 2010, Ray & Street, 2001). The individual who becomes the caregiver of an aging or elderly family member faces the unique challenge (Ray & Street, 2001) of acting in the family member's (patient's) stead in the acquisition of a quality interpersonal interaction (Cheraghi-Sohi et al., 2008). alongside attempting to satisfy needs of the caregiver role (Funk, Stajduhar & Cloutier-Fisher, 2010; Lévesque, Ducharme, Caron, Hanson, Magnusson, Nolan, & Nolan, 2010, Ray & Street, 2001), when interacting with healthcare workers. The caregiver/family member dyad is one in which the objective of providing the best care for the family member is grounded in a history of feelings about love, duty and obligation (Ray & Street, 2001). Caregivers report frustration about non-supportive and ambiguous interaction with healthcare workers (Neufeld, Harrison, Stewart & Hughes, 2008; Neufeld & Kushner, 2009).

Additionally, while the caregiver may want services for the family member, there are various reasons he may fail to ask for them or refuse them altogether (Funk, Stajduhar & Cloutier-Fisher, 2010; Montgomery & Kosloski, 2009). Among findings by Funk, Stajduhar & Cloutier-Fisher (2010), the most salient was caregiver tendencies to put the

family member needs ahead of their own. Caregivers also report fears that use of services is an indicator the family member health is declining, and that use of services negatively reflects on his ability to manage his role or cope with his role (Funk, Stajduhar & Cloutier-Fisher, 2010). Further, the service schedule may be out-of-synch with the caregiver schedule and conflict with the caregiver's primary concern of the family member's immediate needs (Funk, Stajduhar & Cloutier-Fisher, 2010). In other words, the time it takes to contemplate and ask for services detracts from the time the caregiver would otherwise use for the family member (Funk, Stajduhar & Cloutier-Fisher, 2010).

In a model of caregiving through end of life (EOL) (Penrod et al., 2012), identified a repetitive process in caregiving in which changes in the health of the family member disrupt the normal caregiving routine with an immediate need. The caregiver must evaluate the change and options to meet the challenges of the change, with the goal of returning the caregiving process to normal (Penrod et al., 2012). Over time, the caregiver expectation shifts as the family member's needs change or as the family member level dependency changes, and the caregiver response to change is to adjust his role identity, change his behavior, seek services, or all of these (Montgomery & Kosloski, 2009, Ray & Street, 2001). The congruence/incongruence of the service with the caregiver task and the meaning the caregiver gives to the task introduces an element of stress the caregiver must act to decrease (Montgomery & Kosloski, 2009, Ray & Street, 2001). Other factors of the caregiver context that influence these responses include the family norms, social rules, and culture, and the influence of the caregiver with the family member (Montgomery & Kosloski, 2009).

Advance directive

Among rights in the Consumer Bill of Rights and Responsibilities are the right to participate in treatment decisions and confidentiality of health information (DHHS, 1998). The right to participate includes communication between the patient and the healthcare provider that enables the patient to make an informed consent to participate in or forego treatment (DHHS, 1998). Included in the right to participate is the right to use advance directives such as a living will and durable powers of attorney for health care (DHHS, 1998).

The intent of the advance care directive is to support the patient right to an active role in healthcare decisions (AMA, 2014). The advance directive is a legal document a patient may complete that informs the physician of the patient's preferences about end-of-life (EOL) health care (AMA, 2014). In some situations, active participation in healthcare decisions by the patient is not medically possible (AMA, 2014) and in some cases, individuals may experience increased anxiety or depression and reduced satisfaction with the healthcare transaction if encouraged to participate in decisions about their healthcare (Belanger, Rodriquez, & Groleau, 2011). While research shows most patients care about and want to participate in healthcare decisions, a significant minority of patients prefer that someone else makes healthcare decisions (Belanger, Rodriquez, & Groleau, 2011).

As part of the advance care directive, the patient selects someone to act as his agent or proxy in the health care decision with what is known as a durable power of attorney (DPA) for health care (AMA, 2014; NHPCO, 2015). The DPA for health care is

an individual the patient trusts to act in the patient's stead in communication about the patient's wishes for end-of-life care medical decisions (AARP, 2015; NHPCO, 2015).

The confidentiality of health information (DHHS, 1998) means patients have the right to feel that information shared with a physician remains confidential and is not disclosed to other parties without the patient's express consent (AMA, 2012). Healthcare providers may only share protected information with caregivers if the patient has designated the caregiver as his proxy using the DPA for health care and that document is part of the patient's record (Hodgson, Mendenhall & Lamson, 2013). As a documented DPA for healthcare the caregiver is an established member of the patient's health care team who is also entitled to informed consent (Hodgson, Mendenhall & Lamson, 2013).

Social Cognition

Meeting a new person is a sensory experience of receiving and organizing information in a process of social perception. Our first impressions are immediate and selective in the sense that we are only able to focus on a little of everything else going on around the person we are meeting (Oskamp & Schultz, 2005). The organization of information is along a structured assimilation of a whole that is stable and meaningful because of the way it is organized (Oskamp & Schultz, 2005).

Unlike perceptions of nonhuman or inanimate objects social perception includes assessment of intentions and personality in a causal sense, that, people do things, act with intent, and have personalities (Oskamp & Schultz, 2005). In this sense, social perception is a dynamic interaction in which behavior changes as one person responds to the other (Oskamp & Schultz, 2005). Social perception is also assumptive as not all emotion or

attitude is readily observable (Oskamp & Schultz, 2005). Because social perception is subjective, it is more disposed to error than perception of nonhuman or inanimate objects (Lench, 2009, Oskamp & Schultz, 2005). These errors occur in the heuristics and schemas of the user and by way of biases and prejudice (Oskamp & Schultz, 2005).

Heuristics

Once received there are several ways information is refined for use in decisions and further interaction. A heuristic is an informal directory that enables quick assessments of which three are common. First is the availability heuristic consisting of available or salient data more readily remembered that enables estimates of the probabilities of an event (Oskamp & Schultz, 2005). Secondly, an adjustment heuristic uses a baseline value that can be adjusted for use in realistic predictions of behavior (Oskamp & Schultz, 2005). In most cases people will use their own experience, which causes an underestimate or overestimate of the probability others will behave as they do. Lastly, the representative heuristic utilizes information the user thinks is representative of a group to predict behavior of members of that group. The common disadvantage of this heuristic is users ignore other useful data and project unreliable or invalid probabilities (Oskamp & Schultz, 2005).

Schema theory originated as a way to comprehend how a person's cultural experience influences thought in transactions with others (McVee, Dunsmore & Gavelek, 2005). The human consciousness purposefully accesses information in its schema and processes it in decisions about choosing a particular action (Bandura, 2001). These agentic acts produce outcomes with some future in mind (Bandura, 2001). The individual

arrives at a successful end-goal that meets personal standards of satisfaction via self-regulation (Bandura, 2001). Self-regulation, then, refers to the tweaking of the process in ways that assure an outcome compatible with personal standards and minimizes potential for dissatisfying results (Bandura, 2001).

Social Power

Social power is an important group dynamic (Pierro et al., 2013). Leaders use social power to encourage compliance from followers (Pierro et al., 2013). Where the goal is follower commitment to organizational goals, a leader can choose from different power bases to increase commitment, which may vary by leader styles (Raven, 2008). In most cases a leader's motivation is clear to the follower (in the case of caregivers, it is the health and well-being of the family member). The choice of power base then is one that is determined to be the most efficacious. However, this may vary by how the leader views the follower as well (Raven, 2008).

Social influence is defined as the potential an individual has to change another individual using available resources (Raven, 2008, Pierro et al., 2013). A power base is an example of an available resource. Power bases may be expert, legitimate, reward, information, coercion and/or referent (Raven, 2008, Pierro et al., 2013). Power bases are commonly discussed in organizational literature but individuals have them as well, for example, a parent with a child, an older sibling with a younger one, a pastor and congregant, etc., and among peers such as coworkers, friends, neighbors.

Information has power to the extent the leader is able to persuade another **to** change how something is done (Raven, 2008). It is socially independent in that although

it is initiated by the leader, the follower, having been convinced of the value of the change, embraces it cognitively and accepts it, needing no further intervention (Raven, 2008, Pierro et al., 2013).

Coercive and reward power, on the other hand, are socially dependent (Raven, 2008) as the target associates the change with the person who initiates the directive for change (Pierro et al., 2013). For compliance or performance for example, rewards occur in the form of incentives, a raise or promotion, or an increase in autonomy (Raven, 2008). When a leader resorts to threats to bring about compliance he is using coercive power with negative consequences for non-compliance. Coercive methods also require monitoring to assure ongoing conformance with the change request (Raven, 2008). Coercive and reward power may be impersonal or personal depending on whether the leader likes or dislikes the follower (Pierro et al., 2013).

Referent, legitimate, and expert power are socially independent power bases, requiring no further monitoring once accepted by the follower (2008). A leader has expert power when the follower perceives that the leader's knowledge, experience or insight is superior to that of the follower and the leader's direction is therefore superior (Raven, 2008).

If in the follower's view a leader's position entitles him to expect certain compliance (i.e., supervisor, minister, doctor) the leader has legitimate power. The follower accepts the requested change without the need for further monitoring (Raven, 2008). Subcategories more clearly describe how the interpersonal relationship influences agreement with legitimate power (Pierro et al., 2013). Specifically, social norms may

dictate obedience by persons of less power (children obey parents, students obey teachers, etc.) in formal or informal social interaction and reciprocity where there is some obligation to reciprocate (Pierro et al., 2013). An equity norm can motivate a leader to compensate hard work or remedy to individual who has suffered harm and social responsibility norms predispose offering help to someone who needs assistance (Pierro et al., 2013).

A leader has referent power when the follower sees him as a good example to follow (Raven, 2008). Such an implicit assumption is related to the concept of prototypes. Leadership theory posits followers engage their assumptions about leaders when determining how they will respond to leaders (Van Quaquebeke, Graf, & Eckloff, 2014). Such leadership prototypes become benchmarks for use in determining when a leader is a good or poor fit for the follower expectation (Van Quaquebeke, Graf, & Eckloff, 2014). Ultimately, the follower's perception of the how the leader fits his prototype, has an effect on how willing the follower will be to accept the leader's referent power.

The six power bases may be further differentiated as harsh or soft (Pierro et al., 2013). Followers are more agreeable to a soft power base, which generates more positive outcomes for the individual and the organization, however a leader's style has much to do with what power base he chooses to utilize (Pierro et al., 2013).

Leadership prototype

People actively select information from their environments for use in constructing schemas they use to assess and interact with the environment (Bandura, 2001). A leadership prototype of a leader is one such schema (Van Quaquebeke et al.2014).

Leadership theory poses individuals' implicitly held beliefs about leadership form their responses to leaders (Van Quaquebeke et al.2014). The extent to which follower prototypes of a leader matches what a leader is really like affects the follower response to the leader (Van Quaquebeke et al.2014). These abstract schemas set the individuals' expectation for leadership behavior and serve as a basis for judging the leader's behavior as well as making decisions to support or not support the leader (Van Quaquebeke et al.2014). When the leader fits the individual's perception of a leader, he is more favorably viewed (and followed) than if he does not fit the individual's perception of a leader (Van Quaquebeke et al.2014).

Attribution Theory

Attribution theory asserts people judge interaction by internal/external loci of control and whether how they feel about whether they had a choice or something else controlled the outcome (Karl & Peluchette, 2006). Further, in the consumer satisfaction sense, people make judgments about whether the interaction will change or stay the same.

Attribution means to infer something about ourselves or others without having observed it (Oskamp & Schultz, 2005). The attribution processes of social cognition gained attention in the 1970s through the 1980s, particularly as it affects causality of behavior or outcomes but also how we judge responsibility for behavior or an outcome (Oskamp & Schultz, 2005).

Human Bias

Imperfect human judgment may employ systematic biases when judging others (Kerr, MacCoun, & Kramer, 1996). Such biases rise from various processes people

utilize to facilitate understanding and are useful in making decisions or coming to conclusions in often, constricted time situations (cite). Individuals, as well as groups, possess biases (Kerr, MacCoun, & Kramer, 1996). When a consumer interacts with a healthcare worker group, he may easily overcome his bias but when that consumer becomes part of a dyad, as in the healthcare worker/caregiver dyad, the dynamics are different. Overcoming bias for the sake of outcomes for the consumer may be a different process.

In the course of understanding situations, people analyze reasons why they and others behave as they do. Often the conclusions people come to are biased. Imperfect human judgment may employ systematic biases when judging others (Kerr, MacCoun, & Kramer, 1996). Such biases rise from various processes people utilize to facilitate understanding and are useful in making decisions or coming to conclusions in often, constricted time situations. Individuals, as well as groups, possess biases (Kerr, MacCoun, & Kramer, 1996).

Observer attribution bias occurs when an observer associates another's behavior to a disposition that is stable over time, but the person under observation perceives situational factors as reasons for the way he behaves (Harari & Hosey, 1981). In a dyadic relationship, the consumer is more likely to blame the provider if the service failed to meet his expectations (Cowley, 2005). However, while the idiocentric individual whose focus is on himself may not change his initial assessment, an allocentric individual whose focus centers on others, may change his assessment when considering situational factors

except if they sense potential dependence on a provider that has “behavioral control” (Cowley, 2005).

Blame for failed service encounters can extend to others in the provider network (i.e. referrals to specialists) as well as to the originating provider (Tax et al., 2013). Constraints on what provider is available in a referral network can exacerbate issues with the primary physician if the transaction proves unsatisfactory (Tax et al., 2013). On the other hand, a less constrained referral network can pose additional challenges for the consumer to coordinate, and the outcome is more likely influenced by how the consumer performs in this role (Tax et al., 2013).

Consumers may demonstrate bias by judging an encounter with a provider in a referral by comparing that experience with his experience with the primary physician. Such bias may cause the consumer to overlook some short comings and result in a unified assessment in which each individual experience is obscure (Tax et al., 2013). Consumers may have an expectation for similar or same quality of experience throughout referrals to other providers including that the initial provider has responsibility to correct failed service delivery or unsatisfactory experiences (Tax et al., 2013).

Despite being inundated with information to facilitate beneficial choices, choosing the recommended action is not likely if people do not believe the risk applies to them personally (Lench, 2009). A human tendency toward the belief that they will experience desirable outcomes leads to a pervasive bias toward the improbability of negative outcomes (Lench, 2009).

Social exchange theory asserts that people need to feel a relationship is reciprocal in order to remain active in the relationship (Kaiser & Hogan, 2010). In the case of a work relationship, follower engagement is a factor of how fairly the follower perceives he is treated. The leader-member exchange theory holds that mutual trust and respect have to develop between members if groups are to be effective (Kaiser & Hogan, 2010).

Learned Helplessness

Early attribution theory posed that repeat exposure to unsatisfactory conditions and outcomes over which the individual feels he has no control, results in less learning and increases passive responses (Huang, 2012). Learned helplessness could be a consequence and, overtime, might habitually affect an individual's motivation to participate (Huang, 2012). The habituated response is a product of the person's attempt to understand or explain his experience and may be influenced by cues from the environment. Examples of environmental cues may be observations about how others behave in a similar or same experience, information from others (in a similar or same experience), stereotypes, (Huang, 2012) and prototypes (Van Quaquebeke et al.2014).

Self-efficacy

A conceptual framework of positive aspects of caregiving in dementia describes factors of a positive caregiver experience as flowing from the caregiver's sense of self-efficacy (Carbonneau, Caron & Desrosiers, 2010). Self-efficacy has to do with an individual's expectation for favorable outcomes and, as such, play a significant role in behavior (Bandura, 2004). High or low efficacy can influence an individual to self-improve to overcome obstacles or difficulty or abandon the effort respectively (Bandura,

2004). In the case of the caregivers, those with high efficacy are able to see positives, even if the situation is negative whereas those with low efficacy dwell more on negative factors (Semiatin and O'Connor, 2012). Recent research has shown caregivers report positive experiences that can mitigate the negative consequences to their mental and physical health (Semiatin and O'Connor, 2012). Caregivers who report a positive experience have been found to have a sense of gratification with their experience, report a heightened sense of subjective well-being, experience less depression and symptoms of burden, better health, and, as a group, more likelihood to continue in the caregiver role than caregivers who did not report a positive experience (Carbonneau, Caron & Desrosiers, 2010.) Because self-efficacy is what causes an individual to act or not act, an ambiguous role makes it difficult for the individual to assess self-efficacy and reduces the likelihood the individual will actively assert their self-efficacy assessments (Bandura, 2012).

According to TWA, in work, the individual relies on his experience to develop responses to the work environment (Dawis & Lofquist, 1984) including social interaction (Fan et al., 2013). Correspondence with the work environment is a measure of how satisfied the worker is with the environment over a process of self-regulation of his behavior to meet needs of the environment (Dawis & Lofquist, 1984) including those that involve social interaction (Litchfield et al., 2013). In work, social self-efficacy has been found to factor in successful social group interaction, public performance, management of conflict and ability to ask for and provide help (Litchfield et al., 2013).

The Caregiver Career

Burnout

In their early work Lofquist & Dawis (1969) asserted that in the work relationship, an employee requires certain things of the environment and the organization requires certain things of the employee. The ongoing reciprocal exchange between the employee and the work environment results in correspondence the employee and the work environment seek to sustain (Lofquist & Dawis, 1969). The desire for correspondence with the environment and the effort to sustain it is basic human motivation (Lofquist & Dawis, 1969, Dawis & Lofquist, 1984).

Chronic incongruence (Maslach, 2003) or discorrespondence (Lofquist & Dawis, 1969, Dawis & Lofquist, 1984) between the employee and the work environment ends in exhaustion and an erosion of motivators such as passion and commitment to the job (Maslach, 2003). Such protracted job stress may lead to employee burnout (Maslach, 2003). Burnout dimensions as described by the multidimensional model include overwhelming exhaustion that causes the individual to have a cynical response to the job and detachment from the job and feelings of decreased self-efficacy (Maslach, 2003).

Research supports a relationship between burnout and occupational stress and burnout and levels of support in nursing home direct care staff (Woodhead et al., 2014). Direct care staff reporting high levels of support from supervisors, coworkers, family and friends scored lower on the Maslach Burnout Inventory (MBI) than workers reporting less support (Woodhead et al., 2014, Hamann & Foster, 2014). Nevertheless, the overall

finding of this study was that job demands have more effect on increasing burnout than resources have on decreasing burnout (Woodhead et al., 2014).

The Healthcare Transaction

Boundaries

In work, the worker and work environment interact in reciprocal ways for the good of both wherein organisms respond to an environment in potentially many ways and under many different conditions (Dawis & Lofquist, 1984, Eggerth, 2008). The interaction model of the TWA framework describes ways the individual and the environment adjust in their interaction (Dawis & Lofquist, 1984, Eggerth, 2008) in a process similar to reflexive negotiation (Ray & Street, 2001). Adjustment occurs by way of analyzing the level of trust associated with various support relationships and the individual's choice or preference for support options (Ray & Street, 2001). The caregiver and family member dyad develop from existing relationships and roles (Montgomery & Kosloski, 2009, Ray & Street, 2001) wherein both members construct trust from their faith in their continued relationship.

Trust of support (family, friends, professionals) can mitigate issues of burden when caregivers are able to perceive that support responded to the demands of care, the difficulties of inconsistent disease trajectories, continuous loss and caregiver need to manage the care of the family member (Ray & Street, 2001). Trust of support changes with change in the needs of the family member with trust and use of services declining when caregivers find diagnoses too hard to understand or too complicated (Funk, Stajduhar & Cloutier-Fisher, 2010; Montgomery & Kosloski, 2009, Ray & Street, 2001),

or when recommendations do not seem to fit the dyad's need (Funk, Stajduhar & Cloutier-Fisher, 2010; Montgomery & Kosloski, 2009). For example, when, in the case of healthcare workers, the worker demonstrated a lack of knowledge or skill, the caregiver's trust of that support option is undermined and the caregiver burden increases (Ray & Street, 2001). Additionally, healthcare focus on expert control and neglect of caregiver knowledge increases strain on the trust between the caregiver and the family member (Ray & Street, 2001). In a team approach, the caregiver partners with healthcare, producing more trust and reducing caregiver burden and stress (Levesque et al., 2010; Ray & Street, 2001).

A factor related to continued trust of supportive relationships as well has to do with boundaries. Part of the caregiver role is to preserve the dignity of the family member by respecting issues of privacy, causing caregivers to need to renegotiate established levels of trust with support services and healthcare so that issues the family member, caregiver and family wish to be private remain private (Ray & Street, 2001)

Disengagement

Persons reaching age 65 have an average life expectancy of an additional 18.6 years (19.9 years for females and 17.2 years for males)., In 2008, 13% of people in the United States were age 65 or older. By 2030 this number is expected to increase to 72 million or 20% of the population (Older Americans, 2010, p XIV). For various reasons, such as earlier releases from the hospital, longer life expectancies, and medication that enables life with chronic illness, people find themselves caring for family members in the home (Net of Care, 2011).

Some tasks caregivers assume for their family member include personal cares, transportation and coordination of medical visits (Net of Care, 2001). They also perform daily household activities including cleaning and shopping and management of finances (Net of Care, 2001). Caregivers may coordinate medical care including dispensing medication, communicate with the medical team, provide companionship and emotional support, and coordinate services (Net of Care, 2001).

One method used to distinguish the (informal) family caregiver from the formal caregiver in long-term settings is by tasks they perform (Levy-Storms & Miller-Martinez, 2005). The family caregiver may pay bills, keep the family member company, read to the family member, and be involved in the selection of doctors. The formal caregiver performs bathing, feeding, etc. that are considered technical tasks. However, in some instances, family caregivers of a family member in long-term care may perform these tasks as well (Levy-Storms & Miller-Martinez, 2005).

In their effort to understand the true magnitude of people involved in caregiver roles Giovannetti & Wolf (2010) conducted an analysis of eight national surveys reporting from as few as 2.7 million and as many as 36.1 million individuals having caregiver responsibilities for aging adults. Variances occurred according to the definition of caregiver. The range of caregivers included care for children to aging adults, care for persons with disabilities, short term or long-term care, whether the caregiver is a family member, or if the caregiver receives remuneration, etc. (NFCA, 2012). Caregivers are further differentiated by the age of the recipient of care if the care occurred within 12 months of the survey, and if care included activities of daily living (ADLs) and/or

instrumental activities of daily living (IADLs) (NAC & AARP, 2004). In 2007, 66% of aged 65 or older needed assistance with IADLs and this number increased for those over 85 years to 70 percent (Older Americans, 2010).

The third Caregiving in the U.S. (2009) study demographics of caregivers concludes that caregivers are mostly women with an average age of 49, three years older than reported in the 2004 survey (National Alliance for Caregiving, 2009). The average age of care recipients is 69 and the caregiver role lasts just over 4.5 years on average (National Alliance for Caregiving, 2009). The 2009 data indicates caregivers have increased use of supportive resources as well (National Alliance for Caregiving, 2009). However, more participants report needing assistance and information (National Alliance for Caregiving, 2009).

The 2009 data indicates caregivers do not report excessive emotional, physical, or financial burden but financial and emotional burden may be increasing since 2004 (National Alliance for Caregiving, 2009). Most (57%) report very good or excellent health. Fair or poor health reports increases with the length of the caregiving role averaging 17% of respondents, compared with 13% reporting poor health and 61% percent reporting good or excellent health in the general population (CDC, 2009).

No two caregiving situations are the same, so each caregiving process and each caregiver experience is necessarily unique (Montgomery & Kosloski, 2009). Circumstances that created the need for the caregiver role, corresponding expectations of the caregiver role, and each caregiver family and cultural history are all very different (Montgomery & Kosloski, 2009). Additionally, the caregiver role is not one that springs

independently but is an extension of an established role in an existing relationship that adapts and adjusts to meet changing demands (Montgomery & Kosloski, 2009; Schumacher, 1995, Ray & Street, 2001). The caregiver role acquisition occurs via a transition of the family role by way of interaction within the family caregiver and the family care recipient dyad and interaction of that dyad with others (Schumacher, 1995).

Caregiver adjustment to changing roles

Supporting the family caregiver, then, necessitates some understanding of the caregiver and inconsistencies across caregiver experiences including changes to the caregiving context that occur over time (Montgomery & Kosloski, 2009). The caregiver is challenged to cope with change by adjustments in caring dynamics for an aging family member and the associated stress (e et al., 2012, Ray & Street, 2001). As a matter of course, the caregiver role expectation shifts as the family member needs change or as family member dependency increases, causing the caregiver to adjust his role identity or change his behavior to accommodate the change and/or seek services to decrease the need (Montgomery & Kosloski, 2009).

For example, a caregiver choice to not subscribe to services, discontinue a service, or express dissatisfaction with a service (Montgomery & Kosloski, 2009) is a form of a disengagement strategy. If the caregiver perception is that the service does not focus on the core source of the caregiver need (Montgomery & Kosloski, 2009), the decision for an alternative solution represents an active choice (Dawis & Lofquist, 1984). Family norms, social rules, culture, and other family are factors of the caregiver context that influence decisions (Montgomery & Kosloski, 2009). Most important is the influence

of the caregiver/family member dyad, which is often a mutual effort based on trust, for the good of the family member (Ray & Street, 2001). As a matter of course, the caregiver expectation shifts as the family member's needs change or as family member dependency increases, causing the caregiver to adjust his role identity, change his behavior to accommodate the change and/or seek services to decrease the need (Montgomery & Kosloski, 2009). The congruence/incongruence (Dawis & Lofquist, 1984) of the service with the caregiver task and the meaning the caregiver gives to the task introduces an element of stress the caregiver must act to decrease (Montgomery & Kosloski, 2009).

Caregiver burden (CB) is the stress and adjustment of caring for the aging adult. It concerns adjustment of the caregiver to changing roles, threats by challenges in caregiving and changes to the family member, and associated emotional consequences for the caregiver (Garcia-Alberca et al., 2012). We can conceptualize caregiver coping in terms of two main strategies of engagement and disengagement (Garcia-Alberca et al., 2012). The caregiver who utilizes an engagement strategy actively strives to manage the caregiving challenge with change (Garcia-Alberca et al., 2012). Conversely, disengagement strategies simulate withdrawal from the challenge interaction (Garcia-Alberca et al., 2012).

Feelings of inadequacy and thinking that leaving is easier than solving the problem drive disengagement by employees of organizations (Wollard, 2011). Disengagement is a disconnection from the work role designed to protect the individual from threats, real or perceived (Wollard, 2011). It is a manifestation of the individual's powerlessness, an internal emotional process, and an active cognitive choice to withdraw

from the organization and its members (Wollard, 2011). It occurs over time, beginning with the first sense of dissatisfaction resulting from an unsatisfactory experience (i.e. confusing or unfair) (Wollard, 2011). Each successive negative experience adds to the individual's frustration, and he may resort to passive coping in which his focus is on the short-term and responds by following directives by rote (Wollard, 2011).

As the negative experience continues individuals may disengage from their roles to protect themselves from real or perceived threats to their physical and mental/emotional well-being (Wollard, 2011). Disengagement is a behavioral response, in which individuals typically have less energy and motivation for workplace activities and workplace relationships (Wollard, 2011). Disengaged individuals may also be more resistant to the organization and demonstrate reduced flexibility as well as become defensive (Wollard, 2011).

The multidimensional model of burnout (Maslach, 2003) is relevant to family caregiver research as it examines the individual's stress in a social context. In the case of the caregiver, this is in part, the transaction with the health care provider, giving attention to the caregiver emotions, motives, and values (Maslach, 2003). In work, disengagement is the cynical response to burnout in which the employee detaches from the work environment (Maslach, 2003). In the healthcare transaction, a disengaged caregiver may contribute to the dysfunction of the healthcare triad by responding and contributing minimally.

Summary

This literature review describes the growing need for caregivers in the U.S., defines the caregiver role and discusses caregiver adjustment to his role which includes interaction with his family member's healthcare professionals. All of this supports the rationale to study the caregiver from the perspective of work adjustment. The argument is that current social cognition, attribution, and self-efficacy are present and active in the caregiver adjusting to the caregiving role and that conceptualizing these elements in terms of work adjustment can increase understanding of the caregiver role.

The next chapter is the methodology section, which will discuss the choice of the phenomenological method, selection of participants, the methodology used, procedures for data collection and the plan for analysis of the data as well as issues of validity, reliability and confirmability of the data and strategies for an ethical process.

Chapter 3: Research Method

Introduction

The purpose of this qualitative study is to understand whether caregiver expectations and responses in the healthcare interaction are more typical of a person in a work setting than one who is a subject of a healthcare intervention. This chapter discusses the choice of the phenomenological method, selection of participants, procedures for data collection, and plan for data analysis. Also discussed are issues of validity, reliability, and confirmability of the data and strategies for an ethical process.

Research Design and Rationale

Research Questions

The central research question guiding the study is why do family caregivers report non-supportive interaction in the healthcare transaction? Three additional questions sought to elicit information from participant's experience to understand if the caregiver's adjustment to their roles mimics the work adjustment.:

1. How much control does the caregiver experience in the healthcare transaction?
2. In the healthcare transaction, what is the caregiver experience with being valued by healthcare providers?
3. Do caregivers view the healthcare provider as providing leadership?

Themes

The researcher of a qualitative study analyzes responses to interview questions for information that resembles the literature (Strauss, 1987). In qualitative research, broad themes develop from the type and frequency of data produced in the analysis of

participant's responses to interview questions (Creswell, 2003; Maxwell, 2005). Themes also assist with the effort to conceptualize interview questions and a way to organize the data (Maxwell, 2005). The coding of participant's responses in this study was organized initially around themes of the caregiver's perception of his role and identity and the conduciveness of the healthcare transaction to those perceptions. Also, the extent to which the caregiver felt the healthcare professional appreciates the responsibility of the caregiver role and whether the healthcare professional meets the caregiver's expectation of a leader. Other themes may develop from the interviews as well.

The Qualitative Phenomenological Study

The qualitative research design attempts to understand a particular social phenomenon through the identification of underlying characteristics and schemas of the participants in the phenomenon (Maxwell, 2005). The phenomenological researcher describes the lived experience of individuals who have experienced the phenomenon with the intent to reduce those experiences in a way that characterizes the essence of the phenomena (Creswell, 2007). An essential element of the qualitative study is that it is grounded in a conceptual framework easily recognized by the intended audience of the study (Creswell, 2003), which in the case of this study, is a qualitative phenomenological design.

The qualitative phenomenological design aims to develop theory in a somewhat loose structure that enables analysis of data on various generalized levels for a deeper understanding of the phenomenon (Strauss, 1987). Unlike quantitative research, the researcher using a qualitative design does not propose hypotheses but may use a

theoretical construct as a kind of lens through which to view the phenomena (Creswell, 2003). In this study, the theoretical construct is TWA, which describes the individual's adjustment to a work environment in the process of actively and reactively responding to threats of desired correspondence (Dawis, 1984), as an alternative to treating the caregiver as a patient in the healthcare/family member/caregiver triad. The rationale for this construct derives from the literature in which depictions of the family caregiver processes resemble processes of people in work, attempting to achieve correspondence with the work environment. Moreover, the literature persistently refers to the adjustment of the caregiver to his caregiver role.

The qualitative design requires reciprocity between the construct and the data, expected to materialize by the research questions that focus on elements of the work role that are synonymous with the caregiver role as described in the literature. Because there is no research on this topic and because the caregiver role in the healthcare transaction or, in general, is not the typical worker/work environment described in TWA, it is possible to utilize a priori theory (Creswell, 2003) to analyze the phenomena.

Methodology

Participant Selection Strategy

With a vast and varied population of family caregivers, a purposeful sample of middle-to-late age individuals caring for an aging parent is the primary selection criteria. Participants may be male or female, have jobs or have no job, be of any education, and live with their family members or not.

Three agencies in Black Hawk County, IA, offer respite services. I contacted each of these agencies to ascertain their interest in participating in this research. I explained the nature of the study and the type of participant I was seeking. I mailed a formal letter explaining the study and requested their assistance in recruiting participants. I anticipated that the three agencies would provide sufficient participants with interest. In the case of low response, I attempted to secure permission from other community-services locations to leave a flyer in waiting areas where family caregivers might see them.

Instrumentation and Role of the Researcher

This study used semi-directed questions developed from the literature on TWA, social cognition, teams, leadership, and self-efficacy to explore the caregiver's experience. I conducted the interviews at an agreed upon time with participants who called into a Free Conference call number. The interviews were recorded and securely stored. I analyzed the data by themes using a qualitative coding system, initially in Nvivo, and later manually. Interviews were expected to last about an hour.

A brief review was offered at the end of each interview to debrief participants and provide an opportunity for any additional questions. Participants were advised of the possibility of a follow-up interview for the purpose of verifying the data collected. All participants received a copy of the transcribed interview in an email and returned them without significant changes. In the event the number of participants fell below the study objective, additional recruiting was planned using the established recruiting method. There was only one cancelled interview, but it did not affect the number of participants needed for the study. In the qualitative study, the researcher is the instrument of the

research (Maxwell, 2005), which required that I pay attention to what I know or my experience so that I did not introduce bias that would damage the study's credibility.

Pilot Study

A research design is never so accomplished that there is no room for improvement (Maxwell, 2005). Pilot studies are usually worth the extra effort (Maxwell). This research included a pilot study, conducted face-to-face with two individuals who were or had been caregivers, with whom I had discussed my study, but who were not aware of the objectives of the study, and who had no knowledge of the interview questions. A pilot study enables improvement of the research design (Maxwell, 2005) and, in the case of this study, an opportunity to practice the interview questions to test their pertinence, relevance, and association with the research questions.

Procedures

1. Contact the agency from which I intend to recruit participants for permission to distribute brochures in waiting areas or client information areas.
2. Send a formal letter with a copy of the brochure to the agency explaining the nature of the study and request their assistance in distributing the brochures.
3. Call recruited participants and thank them for their interest. Explain the study to participants and request permission to email a consent form that includes their option to withdraw from the study at any time and a demographic survey to be returned pre-interview.

4. When participants return surveys and consent forms, call again to schedule a time for the telephone interview. Answer any questions participants have. Explain that there may be a follow-up call to clarify the accuracy of transcribed interviews.
5. Conduct telephone interviews from my residence in a conference call with the participant who calls from a location of his choosing, at an agreed-upon time.
6. Advised the participant I am recording the interview and obtain their consent.
7. Transcribe the interviews verbatim.
8. Perform any necessary follow-up with participants to clarify the accuracy of transcribed interviews.
9. Begin analysis of data.

Data Collection

This research intended to gain an understanding of the caregiver experience in the healthcare transaction as a means for a better grasp of why the caregiver might report feeling unsupported. A phenomenological method of inquiry was most suitable for this effort with its focus on the individual's perception of elements of his reality; the phenomena (Moustakas, 1994). The primary method of gathering data occurred in recorded interviews with participants. Participants responded to semi-directed questions previously aligned with central subtopics associated with TWA. The semi-directed question is optimum for the first-time researcher as a way to simplify the amount of data that has to be analyzed (Maxwell, 2005). The questions focused on the participant's experience with phenomena of adjustment such as power, leadership, schemas for adaptation, and responses to the environment of the healthcare transaction. Field notes in

the form of memos taken by the interviewer during the interview identified possible additional questions, clarified answers given by the participant, and recorded perceptions the interviewer had about the participants' responses, for use in developing categorical observations and themes in the analysis of the data.

I used Free Conference Call, an Internet-based conference call provider, to record data collected in telephone interviews. I notified participants of the date and time of the meeting, and a dial-in number, the meeting ID, and instructions on how to enter the conversation. I saved the recordings of the interviews and play each back individually for data analysis.

Data Analysis

Many qualitative researchers think of data collection and data analysis as simultaneous processes (Creswell, 2003). It is best if first-time researchers transcribe all of the data, but this can be broad for the first few interviews, and then selective, after establishing codes (Strauss and Corbin, 1990). I used a modified Stevick-Colaizzi-Keen method (Creswell) to eliminate researcher bias as much as is possible. Initial coding consisted of identifying categories that related to previously established themes and emerging themes. I then developed textural and structural descriptions and combined them for a quintessential account of the participant's experience with the phenomena. The organization of data for analysis occurred around the central research questions and according to responses that illustrated the participant's conceptualization of their roles as caregivers, issues of power and control, expectations of leadership by the HCW, and indicators of learned helplessness associated with the HCW transaction. I also explored

the participant's caregiver career, looking for responses that reflect their choices for the role, their adjustment to the role, their training for the role, and differences between their role expectations and their role experience.

Data analysis proceeded with an eye for responses that generated additional questions. Memos provided a method to simplify the data for later re-interpretation, keeping in mind the objective to discover new categories and integrate the data in a way that illustrates the relationship between the data and how it developed (Strauss, 1987). This qualitative phenomenological study used a purposeful sample of participants identified as caring for family members. It provided insight into the meaning ascribed to the experience of caregivers in the healthcare transaction, as well as the resulting thoughts, beliefs, attitudes, and implications. Data were collected from interviews and memos, and coded into preliminary categories of caregiver career, knowledge/training, support, team/leadership, and other for thematic content analysis.

Issues of Trustworthiness

In qualitative research, the measure of validity has to do with whatever threats to validity may exist: ways that a hypothesis may be wrong or alternative explanations for a hypothesis (Maxwell, 2005). The relevance of the interview questions to the research questions is a specific threat to validity in this research. To that extent, I conducted a pilot study to assure the relevance of the interview questions and identify possible changes to the interview questions to maintain their reliability to inform the research questions.

The researcher adds validity when reporting findings by referencing other research and pointing out ways that his study is different (Strauss and Corbin, 1990). For

example, current research reporting on the caregiver focuses the burden associated with the stress of the caregiver role in general, whereas this research specifically solicits information that illustrates particular concepts such as schema, bias, power, and control, etc. and their potential relationship with work adjustment.

Researcher bias is a threat to validity in qualitative research when the interviewer is the primary instrument of the research (Creswell, 2003). The researcher should identify potential bias before the study to have a beneficial outcome (Creswell). As a former caregiver, I have personal experience with caregiving and interacting with healthcare professionals as a caregiver. I also have my own experience with work and work adjustment, which has value to this study in two ways. First, I used my own experience to conceptualize topics that helped organize participant responses around developing themes (Creswell). Second, by addressing personal experience, I separated my feelings from those of the participants in an Epoche process (Moustakas, 1994) that minimized the risk of pre-judging the phenomena.

Finally, I conducted member checks. The member check assures the accuracy of the researcher's transcribed data as well as reinforces the participant's significance in the study (Creswell, 2007). In a member check, the researcher asks the participants to review the researcher's transcribed document for accuracy (Creswell, 2007).

Ethical Procedures

Qualitative research is always intrusive to the extent it seeks personal responses from participants and requires an understanding of participant rights and relevant values whenever possible (Creswell, 2003). An ethical study does not put the value of results

above the rights and well-being of the study participants (NIH, 2016). I completed the NIH (2016) *Protecting Human Research Participants* course to assure I understood the rights of human research subjects. The NIH course certification number is 1988763. Additional steps to ensure the protection of the participant and informed consent were taken. These included communicating the objectives of the study, obtaining a written consent from the participant, and addressing any ambiguity of the research questions. Participants received procedures for the interview and a transcript of the interview. Removal of participant personal information and secure storage of the interviews assured the confidentiality of the participant.

Summary

In this chapter, I have discussed the research design and rationale for the study and the qualitative phenomenological approach, along with the research questions and themes. This study will utilize a pilot study to pre-test the interview questions to assure their applicability and flow. In this section, I also discussed the instrumentation of the study, the study procedures, and the role of the researcher. Data collection and data analysis sections provide information about the collection of the data and qualitative methods for analyzing the data. Finally, I have reviewed issues of trustworthiness and ethical procedures.

Chapter 4: Results

Introduction

The 2019 Bureau of Labor Statics report indicates U.S. unpaid eldercare providers exceed 40 million people (BLS, 2019). As such, supporting the family caregiver has garnered considerable interest in areas of practice and policy (Funk, Stajduhar & Cloutier-Fisher, 2010; Lévesque, Ducharme, Caron, Hanson, Magnusson, Nolan, & Nolan, 2010; Montgomery & Kosloski, 2009; Ray & Street, 2001). We know, for example, that the family caregiver is essential and important, a “hidden” healthcare workforce (Lichtenberg et al., 2009), which, considered alongside reports by caregivers of non-supportive interaction (Neufeld et al., 2008; Neufeld & Eastlick Kushner, 2009), prompts interest in exploring the caregiver from a work perspective. While these caregivers do say what bothers them about interacting with healthcare, there is no evidence of how the dissatisfaction originates. The purpose of this study then, was to understand why the caregivers in the Neufeld, Harrison, Stewart, & Hughes (2008) and Neufeld & Eastlick Kushner (2009) studies might report non-supportive interaction with healthcare professionals of their family members. Presumably, the family caregiver fulfills a working role as a caregiver, and may require support that is less like a medical intervention and more like informational and training support for a job. Understanding what influences the caregiver orientation to their roles may provide insights for improving the support of the caregiver role. This qualitative phenomenological study explored the family caregiver experience of non-supportive interaction in the healthcare

transaction for evidence that work experience has a role in family caregiver expectations.

Constructs that guided the inquiry with participants were TWA and Social Cognition.

The central research question was, “Why do family caregivers report non-supportive interaction in the healthcare transaction?” Additional research questions included:

1. How much control does the caregiver have in the healthcare transaction?
2. Does the caregiver feel valued in the healthcare transaction?
3. Do caregivers view the healthcare provider as providing leadership?

The results of this study may provide a new window into the caregiver experience in the healthcare transaction. As active participants in the family member healthcare team, choices the caregivers make augment their caregiving roles. This perspective may help practitioners understand and facilitate the roles of family caregivers. This chapter discusses the pilot study, participant demographics, participant recruitment, study setting, analysis of the data and the coding trajectory, evidence of trustworthiness, and study results.

Pilot Study

Two pilot study interviews took place before commencing data collection in order to identify interview strategies that would maximize data collection, and to evaluate the effect of the interview questions. Participants were a coworker and a friend who indicated an interest in my study. Both participants were or had been a caregiver of an aging family member. Interviews occurred over the phone via Free Conference Call. Both pilot study participants received the same information as the regular participants, completed the

demographic survey, and signed a consent form. Both participants agreed to have their calls recorded, and this researcher then transcribed the interviews. The pilot study participants seemed to conceptualize the questions differently, and because they did not answer all questions, the semi-directed questions were modified after each interview with the pilot study participants.

From these two interviews, I honed skills that enhanced my ability to elicit responses from participants that would be useful, for example, when to introduce a sub-question. This process also led to further revision of the interview questions, simplifying them, eliminating redundancies, and honing their focus on obtaining useful and relevant information. In the end, the semi-directed questions were simple and encouraged a spontaneous response from participants, which I was able to manipulate via redirection and sub-questions. For example, asking the caregiver to describe what they thought caregiving would be like elicited stories of how their role began, initial feelings about their role, strategies they used to develop their role, previous experience with their family member's illness, etc. Responses often enabled exploration of pertinent topics later.

Demographics

Twelve individuals indicated interest in participating in the study. Of these, one withdrew before consent, one withdrew after consenting, and a third had conflicts with scheduling the interview. Nine individuals participated in semi-structured interviews in a recorded telephone call. The length of the interviews was between 64 and 151 minutes, with a mean of 91 minutes. Tables 1, 2, and 3 contain demographic information.

Table 1

Participant Demographic Information

Participant	Gender	Age	Race	Disability
1	Female	50-59	White	No
2	Female	60-69	White	No
3	Male	50-59	White	No
4	Male	70-79	White	No
5	Female	50-59	White	No
6	Female	50-59	White	No
7	Male	70-79	White	No
8	Female	60-69	White	No
9	Female	60-69	Black	No

Table 1 (continued)

Participant Demographic Information

Participant	Disability	Family Member	Family Member Disability	Advance Directive
1	No	Husband	Stroke	Yes
2	No	Mother	Alzheimer's	Yes
3	No	Father	Alzheimer's	Yes
4	No	Wife	White	No
5	No	Partner	Alzheimer's	Yes
6	No	Mother	Alzheimer's	Yes
7	No	Wife	Parkinson's	Yes
8	No	Husband	Parkinson's	Yes
9	No	Father	Old Age	No response

None of the participants indicated they had a disability. Five participants were caring for either a spouse or a significant other and four participants were caring for an aging parent. The family members suffered from stroke (N = 1), Alzheimer's Disease (AD) (N = 5), Parkinson's Disease (PD) (N = 2), and complications of old age (N = 1). Ages of participants were 50-59 (N = 4), 60 – 69 (N= 3), and 70 – 79 (N = 2).

Recruitment

This research used a purposeful sample of middle-to-late aged individuals caring for adult family members. The original sample description expanded from one having caregivers of only aging parents to caregivers caring for any adult family member, which enabled the inclusion of one female caring for her adult partner and spouses of aging adults with AD or PD. A change in sample criteria also became necessary due to low interest by agencies and hospitals in the recruitment process. My original recruitment plan was to contact three local respite agencies, but none expressed any interest. I proceeded to contact two local hospitals, and despite some initial interest by one hospital, they ultimately declined. I then turned to a chapter of Alzheimer's support groups and a local hospice. The local hospice advised me that their support groups consisted of individuals who had lost their family members and who were in the grieving process and did not want to involve them in my study. Independently then, I began exploring Alzheimer's support groups, and there I found an interest and recruited four participants. One support group gave me information about a PD support group, and I recruited two participants from that group. The other three participants were a result of snowballing.

I identified support groups located in six Iowa counties: Black Hawk County, Bremer County, Clinton County, Dubuque County, Fayette County, and Linn County. I attended meetings in all but Dubuque County. Participants were recruited from support groups in Black Hawk County, Bremer County, Fayette County, and Linn County, Iowa (Table 2). One participant from Linn County withdrew, leaving all participants residing in Black Hawk County, Bremer County, and Buchanan County, Iowa. Of the final group of participants (N=9), six came from a support group I attended. Five

agencies/individuals consisting of a hairdresser in a retirement community, a local chiropractor, an occupational therapist, a hospice agency, and a SHIP volunteer took my brochure and distributed it independently. This snowball method produced one participant. The final two participants recruited through snowballing were both referred to me by faculty, one via a Walden residency and another by my chair.

Table 2

Recruitment Data

Participant	Location	Recruitment Method
1	Black Hawk County, IA	Snowball
2	Black Hawk County, IA	AD Support Group
3	Buchanan County, IA	AD Support Group
4	Bremer County, IA	AD Support Group
5	Bremer County, IA	AD Support Group
6	Out of State	Snowball
7	Bremer County, IA	PD Support Group
8	Bremer County, IA	PD Support Group
9	Out of State	Snowball

At the support group locations, after identifying myself to the group leaders and receiving permission to talk to the group, I gave a short presentation explaining the study and invited the members to look at the information I brought, which comprised of copies of a brochure describing the research (see Figures 1 & 2) . I passed around a signup sheet for people to indicate their name and a contact phone number if they would like me to contact them. I was given the names and phone numbers of three participants recruited by the snowballing method and made sure each had a copy of the brochure as well. I then contacted all participants by phone. At that time, I obtained an email address and followed up the call with an email reiterating the purpose of the study and attaching an informed consent and a link to a demographic survey. When I received the informed

consent back via email, I again contacted the participants, and we set a time for an interview.

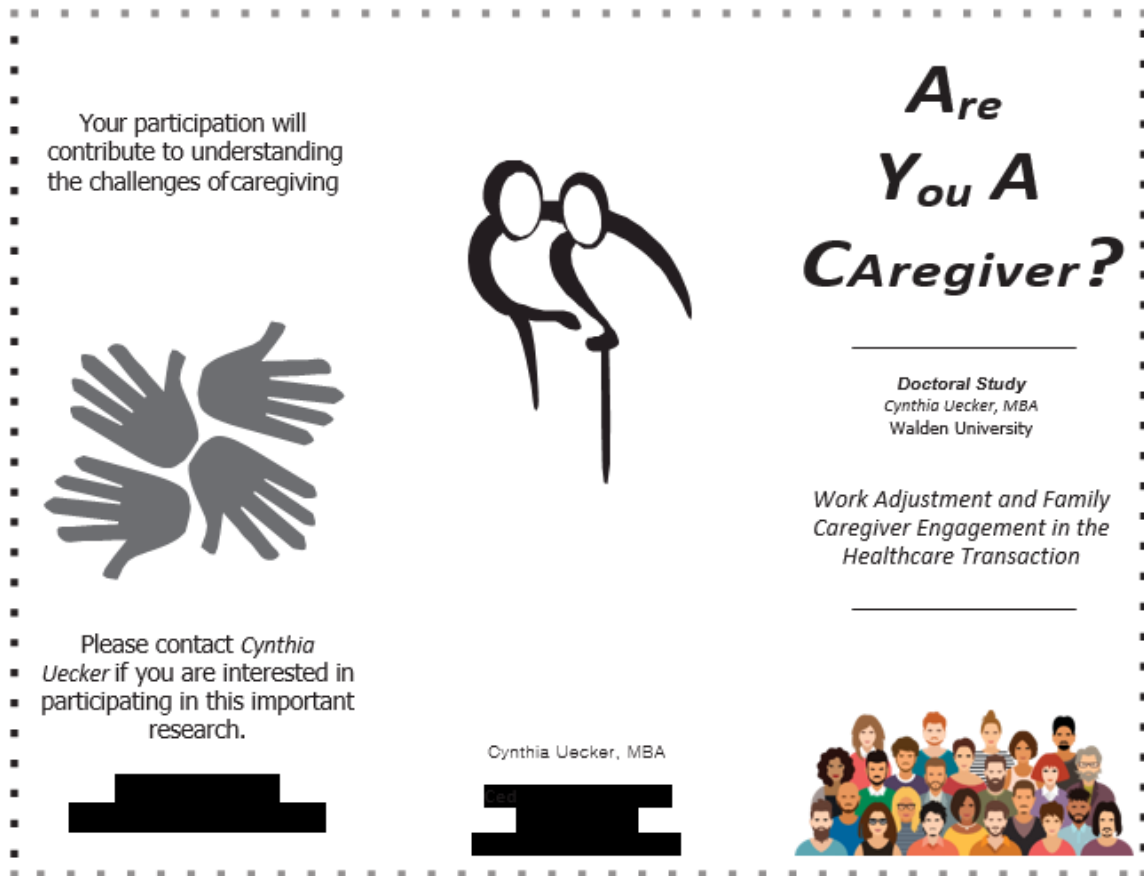


Figure 1. Recruitment brochure front page


In the U.S. 36.1 million individuals are informal caregivers

Some research promotes empowerment of the caregiver but primarily research focuses on healthcare interventions for negative aspects of caregiver burden

The negative effect of non-supportive interaction with healthcare professionals may contribute to caregiver burden

Examining the caregiver role in terms of work adjustment may enable consideration of the caregiver's work experience in adjusting to their role

This qualitative study will examine the experiences of family caregivers who report non-supportive interaction in the healthcare transaction



Cynthia Uecker, MBA

Figure 2. Recruitment brochure back page

Table 3

Participation Education and Work Status

Participant	Education	Work Status	Work Industry	Team Experience
1	High School	Part-time	Childcare	Basic
2	BS/BA	Part-time	Nursing	Basic
3	Graduate degree	unemployed	Research & Development	Management
4	Some college	Retired	Military	Management
5	Some college	FT	Hospital Office	Basic
6	PhD	Retired	Marketing	Management
7	High School	Retired	Manufacturing	Multifunctional
8	Graduate degree	FT	Mortgage	Multifunctional
9	Graduate degree	FT	Military	Basic

Of the demographic survey of the nine participant's family members, seven had an Advance directive designating the participant as the durable power of attorney for healthcare, one had no Advance directive, and one participant did not respond to the Advance directive question. Three participants lived in Black Hawk County, Iowa, three participants lived in Bremer County, Iowa, one participant lived in Buchanan County, Iowa, and two participants lived outside the state of Iowa, one on the east coast, United States, and one in the southern United States. Two participants indicated a high school education, one reported a bachelor's degree, two had some college, three had master's degrees, and one participant had a Ph.D. Two participants were employed part-time, three worked full time, three were retired, and one was unemployed. All participants provided information about their work status, the industries they worked in, and their team experience.

Data Collection

All participants indicated their preference for a time at their convenience for the telephone interview. The setting for the call was from wherever it was convenient for the

participant to call. All participants chose to participate in a conference call and called in from their home. I also called into the conference call from home. All interviews occurred without interruption except for one, which had to be redialed several times during a storm. Despite the care taken to ensure the participant understood where we left off and where we were beginning again, this may have inhibited the flow of information shared and received.

The recording of the conference calls was with the participant's consent. Participants received access to a demographic survey using a link to Survey Monkey provided in their first email. Saved copies in a secure file contained no identifying information except the participant's survey number.

A list of semi-directed questions comprised the interview. It took some time to schedule and conduct all nine interviews, during which I listened to responses and began transcribing. I kept memos to guide the coding process and facilitate recall in the analysis stage.

Setting

There were no organizational dynamics in this study. Recruitment was from support groups and in the snowball method, and as such their place of work and work conditions were not factors. Other than circumstances or stress related to fulfilling their caregiving roles, to the best of my knowledge, none of the participants were undergoing any trauma.

Data Analysis

Bias

Early on in the proposal stage of this paper, I considered my own bias. Perspectives influencing options for aging individuals include healthcare in general, care facilities (LTC, Independent Living), hired companions and home health, and family caregivers, to name a few, vary widely, and are not always perfectly aligned with my perspective. My bias for the choices I made while a caregiver and in work with the disabled and the elderly, became particularly salient as soon as I began interviewing participants. It was at this juncture that I engaged in the Epoché process (Moustakes, 1994). The Epoché is the process of setting aside one's preference for thinking about things to allow a fresh view of the phenomena (Moustakes, 1994). Revisiting this process enabled me to focus on refraining from allowing my viewpoint to influence the way I responded during the participant interviews and freely encourage participants to continue with their point of view. This effort to employ Epoché continued throughout the coding of the transcripts as well and proved an extraordinarily assistive and competent process for identifying information to which I might otherwise not have attended.

Coding Trajectory

The coding trajectory began in chapter three with the development of interview questions designed to answer the study's research questions following Creswell (2003) and Maxwell (2005) recommendations. This initial effort involved conceptualizing a relationship between the caregiver's perceptions of their roles and their expectations of

the healthcare transaction, and the possibility that these might differ from their lived experience.

As stated earlier, after the pilot study, I refined my interview questions to make them broader, and to allow for some flexibility in follow-through. Appendix A has the final list of interview questions. Table 4 shows the relationship between research questions, interview questions, and themes.

Table 4

Relationship Between Research Questions, Interview Questions, and Themes

Research Question	Interview Question Focus	Theme
how much control does the caregiver have in the healthcare transaction?	reasons for role knowledge of caregiving definition of caregiver feelings, worries commitment providence	caregiver readiness for role
Does caregiver feel valued in the healthcare transaction?	advance directive caregiver expectation of healthcare leadership healthcare team caregiver experience with healthcare team	healthcare support for caregiver role
do caregivers view healthcare as providing leadership?	ways of doing new things information obtained communication	evidence of ambiguity in caregiver role

Data analysis began with the transcribing of the interviews. Transcribing was verbatim, and all identifying information removed. The transcribed documents were stored in a secure file. I then sent copies, along with my proposal and interview questions, to a third party for initial coding in NVivo. This produced a preliminary sorting of what NVivo calls nodes. The way qualitative researchers talk about data analysis and the terms

they use, varies and so to simplify, a node is simply another term for a code, which is more widely used in the literature when not discussing software coding. In the discussion of the data, I use the term code and stages of coding throughout.

Since interpreting data is a subjective process, influenced by the researcher's objectives, the third-party analysis returned somewhat different results than I anticipated, expressed primarily (in that early stage of analysis) as frequencies. While a qualitative study does not rely on frequency counts, I did use some of that information to compile the demographics section and as a springboard for further analysis. I then proceeded to code manually for a better grasp of the process and the data content.

I listened to the interviews several times and read the transcribed interviews multiple times and accumulated memos sorted by topic and date. Each iteration (review of the data) revealed more about what the participant said and less of a personal perspective. That exercise went a long way to reduce the effect of personal bias on what was becoming the data set. Personal bias seemed mostly eliminated by the stage of organizing data for categories and themes.

The initial coding phase is also called open coding. In this phase, I was looking for any salient information in the transcribed interviews and writing memos about my perceptions of the data. This stage involved applying a code to label particular phenomena, such as 'reasons for becoming a caregiver.' Codes received a color, also used to highlight relevant text. The color coding became useful as I progressed through all of the interviews, making it possible to identify and select sections of text that were pertinent to the code and copy that to a separate document for that code, for further

analysis. After several iterations of these processes produced no new codes, I considered the open coding phase completed.

Saturation is a qualitative research term that refers to the point at which it is determined no new information will add understanding. It is employed first in the literature review, in the assembly of research that supports the study effort. It is also employed in the analysis of the data. In the case of initial coding saturation occurs when after many iterations, no new codes appear. Saturation also occurred in the axial stage with the formation of categories.

In the axial stage, the researcher begins to think about relationships between the open coded data. I began by sorting the initial codes into categories that were most compatible with my research questions. At this point, the codes underwent a bit of transformation. There was a consolidation of some codes, and I added a few new codes, retaining the majority of the initial codes. Comparisons of participant responses for similarities and differences also occurred in this stage. For example, I found that participant responses to questions about leadership tended to focus on discussions about their role while the opposite occurred when participants were asked about teams, In the case of the latter, participants were less sure about who the leader of the team should be.

In the final stage of data analysis, called selective coding, the goal is to reduce lengthy comments to more brief statements whenever possible, ending with one or two keywords, that capture the essence of the code's relevancy. Table 5 shows a few of the selective codes used in the development of this study's first two themes.

Table 5

Selective Codes for Themes 1 & 2

Theme	Selective codes
caregiver readiness for role	how became a caregiver knowledge of caregiving role reasons for caregiving role feelings about caregiving worries providence commitment goals and objectives as caregiver knowledge of family member illness
healthcare support for caregiver role	healthcare perception of caregiver caregiver as advocate training by healthcare living will/advance directive information from healthcare leadership evidence of team

Not every participant response provided data for every question. Some answers were more detailed and specific to the interview questions than others. In most cases, the participant had some degree of trouble comprehending the shift from relating their experience with their family member's illness or their caregiving challenge to questions about their work environment and work experience, despite information in the brochure indicating the study's intent to examine the caregiver role in terms of work adjustment. In some cases, it was necessary to repeat the study purpose of exploring the caregiver role in terms of work adjustment, which did enable the participant's acceptance of the questions and allow the interview to proceed.

Evidence of Trustworthiness

This qualitative study takes place in a natural setting defined as a telephone interview in which all participants called in from a place of their choice. In this study, the

researcher is the key instrument, which means the researcher collected the data, in this case, by way of open-ended interview questions. The only questionnaire used in this study was to gather demographic information. While many qualitative studies use multiple methods, only one, the interview, was used in this study because no one has studied the topic previously.

This study used the inductive method for analyzing the data, beginning with larger chunks of participant responses and revisiting and revising those chunks to smaller, more abstract pieces and deductively, to the development of themes. The primary focus of the data analysis was on the meaning of participant responses, making sure to report multiple perspectives. Although categories and themes were part of the development of the interview questions, the interview questions evolved after the pilot study and remained flexible throughout the interviews with actual participants, to allow for emergent information.

I disclosed my background and experience in the methodology section to assure this study was as reflexive as possible, and paid attention to reporting not only when participant responses differed but, when possible, why those differences occurred, to present the findings as holistically as possible.

Credibility

Member Check

Copies of the participant's verbatim transcribed interviews were copied into the text of an email and attached as Word documents. All of the participants (N=9) except one, who passed away after the interview, received the email. Of the remaining eight

participants, four participants responded. Three participants accepted the transcribed interview with no changes. One participant agreed to the transcribed interview but requested the redaction of information about products and specific to his work entities. This information was treated as an aside in the data analysis as it had little relevance to the research questions. As such, the redactions did not affect the data analysis. The participant received assurance of the removal of the information.

Transferability

The results of this study of caregivers could transfer to a comparable study of caregivers with work experience. The detail kept of the study context and coding, and data analysis processes would aid the generalizability of results.

Dependability

With dependability in mind, there is a paper trail of coding and data analysis processes in Microsoft Word and Microsoft Excel documents as well as copies of the MP3 recording of the interviews and the transcribed interviews. A spreadsheet documents the initial coding stages and progresses through the development of categories and final themes as well as the development of the demographic information. The coding spreadsheet illustrates the initial coding in a pseudo-NVivo method. Each code has a color, and the coded material appears in that color in the transcripts, with all information saved in a secure location.

Confirmability

Personal bias was a threat to this study because I had been a caregiver and because I had studied the Theory of Work Adjustment (TWA) many years ago and

considered TWA in work environments for many years since. Because I also have previous experience with setting aside my bias when interacting in work, I was able to conceptualize the effect of my bias and focus my effort objectively. Maintaining my objectivity required considering each participant's viewpoint individually and reporting what they said concisely. In the analysis of the data, I carefully considered each participant's response as uniquely representative of their contexts and as insight into the adjustment phenomenon.

Results

Theme 1: Caregiver readiness for the caregiving role.

Several interview questions explored the caregiver's introduction to caregiving, including how they became a caregiver and what they knew about caregiving.

In the beginning.

The initial interview questions were broad, allowing participants the freedom to situate responses in their individual experiences. All of the participants reported their family member illnesses and disabilities as occurrences in the course of their lives together. Only two participants reported any thoughts about caregiving before assuming their caregiving roles, although others may have had some. Some participants spoke about experiences that influenced their thoughts about caregiving. Some were situations related to either caregiving or illness about others they had known in their life and others reported work experience in healthcare or previous caregiving experience. Most of the participants reported some challenges.

The data produced responses that fit into four general categories of symptoms, influences of personal experience with other family and job-related experience, expression of initial goals, plans, or objectives, and challenges to normal. From these, it was possible to identify a 'beginning' of each participant's caregiver role and its context.

Symptoms.

P8 "Started to notice symptoms...when walking...steps not even, sounded out of balance...swing of arms wasn't consistent either...twenty years ago...he was in his early forties."

P2 noticed mother's memory problems after the death of her father.

P6 said, "It didn't become difficult until her symptoms worsened. She would just completely forget...she would not have any recollection of anything..."

Talking about his wife's diagnosis, P7 said, "it's a scary feeling...it is a downward slope."

Challenges.

P1 said, "In the beginning, ...he was younger; I was younger. Because I was so new at it, kind of like the blind leading the blind."

On overcoming differences in opinion, P2 said, "It bothers me when she says something, and then I say no...I have to be careful."

P3 said, "As soon as (my wife) died, we,...I think I'd already gotten a call that my father was pretty severe... needed to have somebody at this point in the house with him 24 hours a day, and five days after my wife died, I was out here and trying to adjust... By the time I got here, he'd turn hostile. The doctors know nothing, why am I here?"

P4 said, “It doesn’t happen to you, it happens to other people...at first...it’s not real,” then “when I found out that she does have it, I wasn’t too surprised, but I did not expect it to be as encompassing as it is now. You don’t know where you’re going, what’s it’s going to do, how it is going to affect your life.”

P5 said, “Sometimes, I think it is a lot harder than I thought it would be emotionally...the only surprise is...the amount of sadness.”

P6: not having intellectual conversations, that was difficult.”

Influences.

P8 “My grandparents...both had Parkinson’s...both in the nursing home for probably about twenty years each...granted, that was a long time ago, but I knew what they went through, and I knew what, you know, I saw for them what that like.”

P7 said, “I had an older brother that had rheumatoid arthritis, and I was around him a lot, so I knew what it was like when people needed help to get around...I knew what it was like to get him in and out of a wheelchair.”

P2 said, “I worked in a nursing home...so I knew what it would entail eventually...what it would be like.”

P3 said, “My wife had brain cancer...her body wasn’t processing potassium. Her graduate degree was plant physiology so...she worked out...what we needed to do to remove all potassium from her diet... she was living on basically, potassium that was already in her blood system...that was slowing the speed of the cancer that was spreading through her brain.”

P5 said, “As a CNA, it was your job...to be very nice...help them along and stuff. In this situation, I don’t have to be nice...that’s the dynamics of being a couple, so sometimes we don’t have the same thinking...sometimes it is a lot harder...it all depends on the day...if we are stressed.”

Early Plan.

P6 said, “My parents and I lived together, and I knew that I would never ever put them in a senior’s facility or something like that...I just took on the role...as soon as my father passed away, that was it...(mother’s) symptoms all came out...it wasn’t a thought-out process; it ...evolved as the symptoms changed.”

P1 said she knew she would not stop her life to be a fulltime caregiver but, “I just wanted...to see what I would have to go through...to move in with her.”

P2 considered moving in with her mother to keep her independent as long as possible: “I just wanted to see how that would work where she lives.”

Sacrifice and modesty.

Two additional categories emerged in participant self-reports about feelings and concerns. This data is slightly more reflective than accounts of early experience and treated separately. Participants readily acknowledge difficulty and sacrifice couched in modesty.

P1: “It is hard, very hard, (but) I’ve gotten so used to this way of life. I mean, it’s not bad...I don’t want to sound like a pity party.”

P4: “I would never complain.”

P5: “The...surprise is... the amount of sadness I have about it...that’s more than the physical maybe, it is really sad, the disease is really sad.”

P4: “It has affected my life quite a bit, but I’m willing to accept it.”

P7: “It’s something you can’t imagine until you get involved. The challenge (is to not) say ‘hey you can’t do it.’”

P9: “I felt pretty good about (caregiving)...there wasn’t anything I wouldn’t do for (dad)...he was pretty independent...then, ...maybe the last year...started not wanting to go anywhere...didn’t...want to bathe...whatever he wanted, I would just let him.”

Rejection of information from healthcare.

Previous studies indicate caregivers are not always amenable to advice from healthcare (Funk, Stajduhar & Cloutier-Fisher, 2010; Montgomery & Kosloski, 2009) for various reasons. Participants in this study articulated several probable causes to reject information or influence from healthcare providers that included differences of opinion, advocacy, timeliness or relevance of information, and violations of privacy. These were grouped into one category describing reasons caregivers reject information.

P1 described a visit to the emergency room when the doctors were about to discharge her husband: “he had a pulmonary embolism in the lung...was in a lot of pain... I said no...you are not sending him home just because he is calmed down because he is on morphine, and I am going to have to drag him back out here...and they didn’t (discharge him). I just wasn’t going to tolerate it. I am very protective of him...I just walked back there and said you are not sending him home. I will leave so you can’t send him home. I am just kind of a snot like that.”

P2 said, “the doctor handed a pamphlet to me, and I looked at it, but you know, it’s like I don’t need any of that kind of support for my mom at this point; I am not comfortable doing those (online) things.”

In a waiting area, a doctor they did not know approached P8 and her husband. He said he noticed (her husband) had PD, and he had a video he wanted to share about surgery for PD. They felt he had no business approaching them that way because he was not their doctor and knew nothing of her husband’s background. They left without keeping the appointment and did not view the video or mention it to her husband’s neurologist at the next visit.

P9 said their healthcare provider did not talk to her about end of life (EOD), but “there was no need, he would have received care (here) at the house. I never would have put him in long term care.”

After his stroke, P1’s husband was on his feet in the early weeks of diagnosis and treatment when a social worker approached them about signing up for a waiver for financial support, and they declined: “we never thought (he) would never go back to work.”

P6: “My parents and I (have always) lived together, and I knew that I would never ever put them in a senior’s facility or something like that.”

Commitment and providence.

When asked how or why they became caregivers, participants provided details about their relationships and commitment, and insights into how they feel providence had a role. Caregiving roles commonly occur for reasons of culture, and relationship, and

sometimes because of feelings about long term care This affirms what previous studies have reported (Haley, 2013; Montgomery & Kosloski, 2009; Schumacher, 1995, Ray & Street, 2001). All of the participants in this study were either already family or had long term relationships with the person for whom they were caring. Participants in this study also referred to aspects of their lives that seemed to support their reasons to commit to caregiving such as availability, experience, knowledge, parallels with other experience, and fit with established purpose.

P1: “We had been living together and had been together for years, and I said, let’s just do that. I said I don’t work; I can take care of him.”

P2: “I was single, living in an apartment, no house to sell. I kept my same job (an hour away) but only two days a week. I know that moving in with my mom is what God wants me to do because I know it is the right thing.”

P3 was committed to exploring treatment options for his wife, who held a master’s degree in plant biology. They worked with her neurologist and implemented a diet that “starved the metastatic phase of her cancer in her brain.”

P3 is similarly devoted to facilitating options for his father and using artificial intelligence (AI), has developed a device that can “tell me he has gone into an area that is dangerous.”

P4: I’m married to the lady for 43 years, and what she’s done for me over the years, I am glad to do the payback and do what I can for her... she did it for so long I feel now it is my turn.”

P5: "I am taking care of my significant other... he is 19 years older...it is funny because my mom died many years ago, and my dad married someone who is 19 years younger than him. So, my stepmother is in the same position except that my dad is 87 years old... she's in this boat that I will be in sometimes... I think that there was a purpose to that. It is part of my life; this is what God gave us to deal with and we are going to deal with it."

P6: "My parents and I have always lived together and I knew that I would never ever put them in a senior's facility or something like that, so I just took on the role... I took care of my father as well. My mother is 91...she has Alzheimer's... the only thought out portion was I knew that my parents would always live in their home, that wasn't even a question."

P7: "I feel that it's my spouse and I took her for better or for worse, whatever come, I'm not gonna say, 'hey you're sick, I don't want...walk away from you; I will be there with you.'... this here, it's, you don't walk away."

P8: "I don't see caregiver as really that different from companion in my own thinking. From the time we have been married, we care for each other and help each other however we can. So, I guess it's a companion and maybe there are different levels...different degrees...that you have to help your partner but that's how I look at a caregiver."

Theme 2: Healthcare support for caregiver role.

Advance directive

Because the concept of a healthcare team developed from the purpose of the Advance directive, which is to enable someone to designate another person (a DPA) to speak on their behalf (AARP, 2015; AMA, 2015; NHPCO, 2015), and because as a documented durable power of attorney (DPA) for healthcare the caregiver is an established member of the patient's health care team who is also entitled to informed consent (Hodgson, Mendenhall & Lamson, 2013), interview questions explored the advance directive. While seven participants indicated their family members had an advance directive, that they were their family member's designee, and that their family member's healthcare providers had copies of the advance directive, none of those participants indicated any perception that the advance directive was an entitlement to information about their family member from healthcare. In particular, none of the participants showed any knowledge that the advance directive entitled them to assistance (as a member of the family member's healthcare team) by healthcare in their caregiver roles other than information about their family members.

P9 did not understand the difference between financial and medical powers of attorney.

P6 stated that "in a corporate environment, it was typical working with teams." She did not feel the same way about her relationship with healthcare, "the doctor is there for support...he advises me...in a sense...teamwork. It's not his role."

Two participants had specific thoughts about the utility of the Advance directive. P5 stated that she felt the healthcare providers were aware she was her significant other's DPA, "yes, because I'm the one who is with him at those appointments, and I am the one

asking the questions. And I follow up too, as far as contacting the nurse...So yeah, I'm comfortable with that so far."

P4 spoke of a 'spin down,' "get your affairs in order...I went to a lawyer, got the house and cars in my name, durable power of attorney...the biggest thing was getting set up for Medicaid. (The attorney) explained to her what we were doing, so it wouldn't be me explaining it."

Healthcare assistance with the caregiver role

Furthering exploration into the relationship presumed to emerge from the use of an advance directive, participants were asked about the kind of assistance they received for their roles in the healthcare transaction. Their responses produced following categories related to expectations, leadership, team, and information/training.

Expectations.

Except for one participant, none of the participants expressed explicit expectations that doctors would go into detail about what the caregiver should expect in their roles. The exception was P1 who, upon her husband's discharge from one hospital to another, expressed that the stroke doctor provided no information related to taking care of him, "None, no." She assumed that it was because he was going to another hospital, not going home.

Otherwise, the caregivers had some sense of what was typical in a healthcare transaction.

P3: "The doctors did their role. They identified the disease or the disease characteristics, gave me enough information to at least get started on, you know, just

knowing which drugs...what assessments have been made. The interaction with the doctors, it's not your normal teamwork. It is more like you are taking somebody to the barber, getting a service done, and they are released. It is not, to me, teamwork. I don't consider my going to the doctor part of teamwork."

Conversely, while P4 did not feel healthcare should make critical choices for him, he felt their doctor's direction was crucial in his decision making: "I wouldn't have known what to do, what to expect... our family doctor was the one that insisted that I go talk to the people in the nursing home and you know, get set up, but, as far as anybody else, not really...I didn't know what to ask, who do you ask... I think they should have done a little more education to me."

Leadership.

Asked about their perceptions of leadership in general, the participants spoke of leadership at work and in their caregiver role. Some participants were able to connect some experience with healthcare to experiences in work and demonstrated knowledge of and use of job skills such as role-playing, autonomy, and empowerment

P4 described a management style he learned from others and applied himself "this is the way the job has to be done, and this is how I want you to do it, and now you are on your own. If you screw up, come back to me, we'll straighten it out...you work it out on your own, and if you had a problem, you went to (boss), and you'd try to solve it together."

In managing home health agents in her home, P1 focused on making sure that her husband suffered no anxiety during transfers. Despite that she understood the nurses had

more knowledge of some things, about transfers, she asserted that she was expert in what was best for her husband; “they send a nurse along with an aide...we had (the aide) pretend she was (the patient) so she knew where to put her hands...to pivot him...because his weight will take him into the bathtub.”

P9: “I always felt that I was in charge of making the decisions for my dad and that my husband was like the second...the only time (the office) communicated with me was if I (said), that it was my dad, most of the time I waited in the lounge, but I think there were at least a couple of times when they communicated with me.”

P2: “I don’t think it is me that is really in charge right now. I just want to do what my mom wants and whatever she is comfortable with because she can still make decisions about things...but at least I still kind of know how to ask her.”

An interview question asked participants if they considered any member of their family member’s healthcare team a leader:

P7: Not particularly. We have our regular GP, which we see every six months...if we have other problems, we see the neurologist...check on things...once our GP told us to get rid of loose rugs.”

P5 felt the doctor took the lead by discontinuing three of her partner’s AD medications, which was also evidence of him working in tandem with her partner’s wish for “quality over quantity...he talked to us before he did it and said, ‘this is why I am doing it’...I know the doctor listened to me, and he looked at both of us.”

P8: “At first, with the family doctor, that doctor was pretty much leaving, and it was so new to us, and we didn’t know. You don’t just go to a neurologist; generally, it is

by referral, so we were just following the lead of the family doctor.... When the family doctor changed... She referred to the neurologist... maybe the leadership kind of switched more to the neurologist.”

P4: “The doctor...said, ‘I encourage you to do this, but you have to make the final decision about the nursing home.’”

P5: “The doctor...in that they are the top, and then the team leads would be like me, but the team leads are nothing, the manager is nothing without the peons pretty much... they can’t do anything without us; they are nothing without us...I don’t think (doctor) feels that way about us. I would say he’s maybe the manager but (her family member) would be the team lead...for as long as he can because he is the one that is going through this.”

Team.

When asked about their perceptions of being part of a team with their family member’s healthcare professionals, participants responded similarly to the way they did about leadership, mixing their experience with work teams and their perceptions of teams in the healthcare transaction.

P1: “Yes...they call to change an appointment; they just ask for me cause they know I do all this... and if they call, like if I’ve left a message for prescriptions, they’ll call back and say...you know, we changed something, and then the doctor calls back.” Over fifteen years, P1 says working as a team is “huge,” which for them encompassed assistance by various agencies including remodeling of their bathroom by NEIAA, a local

agency that facilitated acquiring a van with a lift, a GoFundMe page that helped pay for a van, and staffing by a home health agency.

P2: “Yes...they talk to her...if she can’t think...she looks at me and then...I answer... it’s teamwork right now, and when she can’t do her part well, then I’ll know when to step in and do more.”

P3: “In the interaction with the doctors, it’s not your normal teamwork. It is more like...getting a service done, and they are released...you go through this door; blood pressure is taken, step, step, step, get your fifteen minutes, you are out the door...It is not, to me, teamwork. I don’t consider my going to the doctor part of teamwork.”

P4: “I don’t really see a team; they were pretty good to me and all that... the support was there, the doctor, but I made the decisions. I don’t know if you would call that a team...it was my decision and will be...from now on. We had hospice in a couple of years ago...she gained weight, and that disqualifies hospice. I didn’t feel encouragement for that...team concept. In the nursing home, they tell me what they are thinking about and ask me what I think. We have hospice again (now), and they come to me and ask my opinion. It is more a team concept now.”

P5: “His daughters rely on me, his doctor relies on me, his nurse relies on me, and (X) relies on me...we all do make decisions together because I am not in charge.”

P6 did not feel interaction with the doctor is teamwork. “It’s not his role...(he) is there for support whenever I need him, he advises me...in decision making.”

P9: “I worked, I had a job, and my husband didn’t at the time, it was easier for him to take my dad to his doctor appointments and be there for him during the day, more

so than I could be there for him. So we worked as a team...(on office visits) most of the time, I waited in the lounge...I wanted to be part of (his healthcare) team, so when they told me...or let me have some input that made me feel good and when they didn't let me have input, after like when the door was closed, and he was in there alone, I felt like I needed to have been in there and talked with them or heard what they were telling him so that I would know..."

Some participant responses about leadership and teams were specific only to their jobs and work experience.

P3: "We called them quality circles... we experimented with new ways of creating teams to have the employees all feel ownership in solutions...it gets back down the chain, and pretty soon you have all collaborated with what changes their technology or their field and what would have to vary to use it and...it gets back to the other person... it's fun; it's pretty much if you don't have that kind of a team stuff doesn't really happen."

P5 said that "(at work) nobody ever really works alone...there is always someone to ask...(caregiving) is very similar...everybody is a contributor to the organization, so we are all a team member."

P7 recalls taking the lead at work. "I...tried to make sure what was going on when we came in...checked in the supervisor's office...what we were supposed to be running for the day...passed that on to other members of the team...how much we had to go...changeovers...clean up."

P6 credits her work experience as a basis for how she thinks about challenges in her caregiving role, In a corporate environment...it was typical working with teams, running teams, working with others to get projects done...being part of teams, having people reporting to you...gave me, prepared me for the (caregiving) role because you think of, not that you've planned, but you know the questions to ask, you think of it logically. You don't just panic, and say what am I going to do I better ask somebody. You say this is what's happening; these are the symptoms, talk to the doctor, let's figure out a solution... So, I think I am more disciplined, aside from the personal aspect, thinking logically what needs to be done to take care of her in the best way. So, in that sense being in a team...teamwork."

P7, who works in machine maintenance said, "Sometimes we would get new supervisors that were fresh out of college, and they thought they had all the right ideas...some of us that had been around for many years had a hard time accepting that." The supervisors wanted to make changes the employees had tried before with other new supervisors. They felt obligated to follow the management team orders "because...they are our boss...I always respect their job as my boss. When they got to know us better, most of them I liked to work with and (I would) say hey, this will not work and let's try this, this is why we have done this. Most would listen...appreciated our input." Comparing that with interaction with healthcare, this participant said, "we talked to the doctors, and they changed her medicine, and that helped... they've always said if that doesn't work out right, give us a call, and we will try something different."

Information/Training

The participants were asked to describe their experience with training for and in their jobs, including what they expected and what they received. Responses indicated a broad cross section of organizational terms related to employee training and development.

P7: “enough information that I can figure it out, either good manuals or a program laid out or the proper personnel to do it.”

P1 described training for a customer service job as consisting of “role-playing...we’d watch videos...our manager...would teach us (values)...certain (common sense) terminology.” In a dispatching job, she described hands-on training and a “kind of...chart...what to do.” When her husband fell ill, “I didn’t even think of stroke because of his age...stroke, unfortunately, is stereotyped...so I didn’t think that, so I was really disappointed in myself from that aspect.” In a staffing position, training was also hands-on, from coworkers. “document...you compromise and work deals...call people in...to cover the patients. Evaluations...every year.”

P4: As a volunteer, “in the SHIPP program...we went through training of the ‘spin down’ where you have to be before you qualify for Title XIX, and the training really helped me. Someone who had not had that training would not know what to do about it.” He described working in military “recreation services...(crossing over) into radio/TV broadcasting...until my last five years of service when I cross-trained into recruiting advertising.”

In transitioning to work from home, P8 described “online course, reading, always required courses that you take, some information for new employees, orientation and that

kind of thing...shadowing my manager and going with her to some of her meetings virtually and shadowing how she did things. She mentored me.” P8 prefers hands-on, “to experience it, to really have an imprint on what I should be doing.” I can’t just read about it to learn how to do it. In a supervisor, she looks for “someone who is organized, responsive, flexible, and understanding. I can reach out to my manager and ask her questions. If she is in a meeting and it is urgent, I can send an instant message, and she will answer me. I do have other teammates on my team that are in other office locations, and I can reach out to them as well. Again, it would depend on the question.”

Participants were then asked about training they received from healthcare for their caregiving roles. Having talked about training for their jobs, participants were somewhat primed to use organizational terms. Responses ranged from having no training at all to specifics about such things as treatments and tests. Participants did recall receiving information about their family member health, and learning associated with performing cares for their family members but none reported receiving information specific to their caregiving roles. Two thought that there was no training available and inferred that maybe training was not possible because each person is different.

P1 stated that she had absolutely no idea of the long term of their situation. As for training, “Not much, actually zero... there is no training to become a caregiver; I trained myself; nobody came here...(the) physical therapist taught us how to do the pivoting, and in the last few years, we have done it our way.” Later, when home health began to come, she found them receptive to learning her way of doing things, “I would train them how to do it... we had her pretend...so she knew where to put her hands on him to pivot him.”

P6 said, “learning from informal and formal relationships...can be “informative...whether it is friends experiencing this or the doctor saying yes, these are the symptoms...there is a difference hearing...from a medical perspective than from someone who is not trained...at first, it seems...obvious...you would listen to those who are more experienced who are the caregivers (but)...you don’t know how knowledgeable (they are). For example, (reaction to changes in) sensory-motor skills...if a caregiver doesn’t know about all of this, then they won’t understand what is happening, and they could probably react differently...the parent isn’t responding...could) go on forever until they realize what’s going on. Whereas...the doctor says well yes, their depth perception has changed, so you need to speak to them face to face as opposed to on the side because they can’t see you...both (are)...valuable because knowing the medical conditions...helps you deal with it more. I would say the majority of caregivers understand to an extent, so I think a combination of both the doctor and the experienced caregivers.

P7 cited help from the pharmacists, “they will go through...questions. We went on a different drug...and she sat down, explained it, what it would do, and some of the side effects...the reason we were on it...has helped a lot. If they have a new one, they check to see how it will interact with the ones we have; we don’t depend on just the doctor. Our family doctor recommended that we see a neurologist...go on the Internet, and ‘that will give you a pretty good explanation of what PD does and how it affects you.’ We did that. He said he could sit there and explain it, but there you can read it over. I printed a lot off so I could re-study it...a lot has followed in procession...several

different stages for different people...I allowed for that.” P7 also said, “there’s no manual. It’s like when you become a parent. Sure, when the kids are small, you think about Dr. Spock, but that didn’t really tell you how to do it. Each child was a little bit different anyhow.”

P8 is comfortable with the flow of information about her husband’s PD from the provider. “There was...no test to say it is PD...more or less ruling out other things...coming to a PD conclusion. Before...annual appointment...husband makes a list of questions...we just go...through the list...he asks questions...I make notes. The neurologists (allows) a lot of leeway, ‘if you want to change you can, you can change this (but not that), you can change by half a tablet.’ He...(provides) parameters... (says to) call...if you need anything...we feel like we’ve got a lifeline...he has referred us to...information...a book...in layman’s terms.”

P9 felt unprepared for when her father needed a urinary catheter and when he took an injection in his stomach at home. They did the basic part...put it inside his body...all he had to do was ...click on...(an external component)...he (father) didn’t let me in on that one... no training for (the injection) either, he just told me where...not in the middle...toward the left or the right side...and that was it...I was glad when that was over...I felt more comfortable (with) the pacemaker than I did about anything...because it required limited help... they could monitor it I guess by phone or all he had to do was answer a phone call and that would be done”

Theme 3: Evidence of ambiguity in the caregiver role

Responses in the interviews consistently evidence a process and evolving understanding of those processes that are different for each participant. Two categories developed from participant discussions of how they thought about their caregiving roles. Interpretive processes highlight the range of participant responses. Ways of organizing elements of experience is meant to demonstrate the variance in strategy that arises from so many different perspectives.

Interpretive processes

P1 said that in work, “nurses just clicked with me, maybe I was easier...the sound of my voice...I just worked with them.” Describes instinctive reaction: “I didn’t have any experience to draw on, I just wasn’t going to tolerate it.”

P2: “Nobody wants to be told what to do... I deal with people like that a lot...they want whatever they want and not what the doctor ordered.”

P3: “When I speak with the biologists, I have...many questions, ...which...confuses my doctor. When I jump between intelligent systems, computers, and people, psychology, looking for what I don’t understand, I say well in the intelligent systems this would happen. How does that compare to the brain? And when I am talking to a neuro-oncologist and say how does this happen, what comparable options are there, and a lot of times I find that I can fill in their holes by what we are doing in artificial intelligence (AI) and he can fill in my holes by saying, yeah we have something like that in our field, it would be in this part of the brain. I turned over all her research to him so he could continue that on.”

P4: “She was forgetting things...I didn’t know...eventually, I started taking over...eventually...everything...when I found out...I wasn’t too surprised...I...took so much for granted...now it is my turn. I needed to listen...it was going to happen to me...get prepared...prepared myself...the biggest and hardest thing.”

P5: “A matter of reminding him of things...not that difficult yet... making sure his needs are met...safety...depends on the day...stress... I don’t know that it is harder than I thought it would be...don’t have scheduled things to do like I did in the nursing home... something you do for someone you love. I don’t think of caregiving as a job...it is my life...part of my life.”

P6: “My parents and I lived together...just took on the role...evolved as symptoms changed...wasn’t a thought-out process.”

P7 feels caregiving is adaptive, wife picked up information about meetings at the senior center...son helps out. He says he is self-taught, has explored many things such as essential oils, and “make sure our home was as handy as possible...minor things. He described an appointment where the doctor came in and said: “it looks like things are under control.” and P7 responded, “maybe on paper but I’ve got some questions, I want answers...After that, when we come in, that’s how he does. I...get her out to do things...exercise class...keep depression away...separation for both of us, to get away from each other.”

P8: “From the time we...married, we care for each other and help each other however we can...(husband) “wasn’t that concerned...‘well we will just take it as it comes and we’ll deal with it’...(we) went to a support group... try to queue into people

we might have something in common with... he is very highly functioning... usually, he doesn't want me to help him unless he asks." They are thinking ahead, "not able to get nursing home insurance...not much we can control about that. I think he worries about me having to take care of him or that he sometimes puts too much on me. But that is just the way it is. We just do the best we can."

P9 decided to have her father move in with her when she had some concerns about cooking behavior..." I didn't have a diagnosis...having heart problems...he wasn't any trouble...he would ride his bike wherever he wanted to go...stopped...about a month before he passed away." She spoke of some difficulty with a sister regarding funeral arrangements, "I chalked it up to the grieving process...something people have to do, including...a little bit of insanity."

Ways of organizing elements of experience

P1: "how to...common sense."

P2: "I know how nurses deal."

Previous caregiving experience.

P2 "Nursing experience."

P3: "I help people find ways to make it happen...things that no answer is known...that would be large costs to the company."

P4: "training of the spin down...to qualify for Medicaid."

P4: "Air Force is a matter of discipline...compliance"

P4: "autonomy was a great part of their success."

P6: “having people report to you...prepared me...(think) logically...the entire picture.”

P7: “farm...was not automated...had to work around it.”

P7: “I knew what it was like when people needed help to get around.”

P7: A Sister, who is a nurse, told him, “you have to ask questions...they are not going to automatically ask you or wait for you to ask.”

P8: “I don’t see caregiver as really that different from companion.”

P8: Because of a childhood memory of grandparents in a nursing home, “I was overwhelmed, ...very scared.”

Theme 4: Support

Participants easily spoke of supportive sources. Non-support group resources consisted primarily of family, friends, and coworkers. The support group was treated as a separate category for its specifics to the caregiving role.

Eight participants mentioned support from family, whether it be a parent, sibling, child, or some other relative. Four participants cited help from friends, both existing and acquired in the support group. P1 was using home health services, and another had hired a permanent live in-aide. P4’s family member was living in an LTC memory unit, and another participant's family member was living in a retirement community that offered a range of assistive services. P5 thought of her coworkers as therapy because she spoke with them often about her challenges. All but two participants were active in a support group.

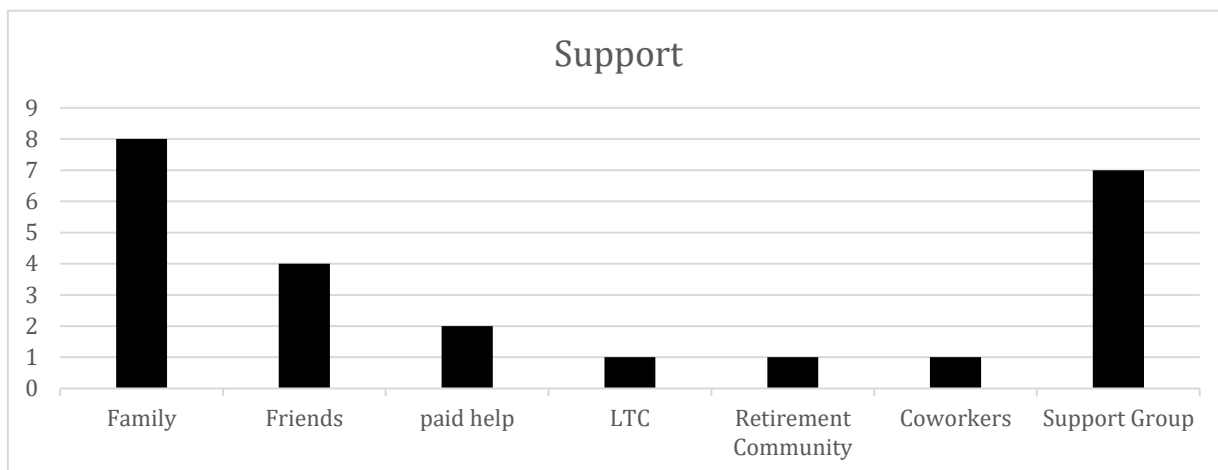


Figure 3. Primary support sources

The support from family ranged from having someone to talk to, occasional assistance with transportation, advice about communicating with healthcare, and discussions about current and long-term plans for caring for the participant's family member.

P1 had worked with some of her family member's healthcare team. She described a relationship that is friendly and familiar..." they call me...they know I do all this...the social worker...sat down with us...went over every detail....as far as family and friends, I (have support), but it's limited."

P2's brother is her mother's financial power of attorney and understood her plans for their mother; her younger brother thought it was fine when she talked to him. "They say, 'if there is anything we can do.'" Her mother's retirement community is supportive. "I went there this morning, ...updated...took her picture...she has a little medical pendant...push the button...they had to check that."

P3's family is prepared to step in when needed..."when (my research) is done, I'm probably going to leave...my daughter will come out...(a) tag team,...I'm getting

support from my kids, cousins...they help between us...planning, the bouncing off...trying to make a backup plan. I'm getting help, the support group, and online I am able to get some stuff...support from my kids, my cousins, and that's the team...basically... The planning, the bouncing off, you know, what are we going to do if it takes more than two years, things like that... We're trying to plan."

P4's family doctor is "really good...pretty much told me that we need to get her into a nursing home, pushed me into it, which I am glad he did...oldest son...understood...I don't think he had any objections...left it completely in my hands...youngest son...kind of denied that his mother was having Alzheimer's...at the beginning...he went along...now he understands...(was) with me when I admitted her to care...the nursing home...always encouraged me...but I didn't know the extent of it until we actually made a decision.

P5 feels it helps 'tremendously' that she works at the hospital where her partner's doctors are officed. "they know who I am...know I am not going to bother them unless I really need help. I really relied on my coworkers...when I had cancer...that's where I am again. His family is amazing, but...when I go to work, that's who I talk to...they are my psychiatrists, my social, my counselors.

P6 has informal support from friends who "have gone through the same thing or are going through the same things. It is informative."

P7: "I have a son less than a block away...he helps out when we need it...a meeting I want to go...my wife...to exercise...take her and pick her up and bring her back home...they are available to do that."

P8: “there were some people from our church that we got connected with.”

P9: “sometimes the nurse would give me some feedback about how to care for him more...if he needed help...they would assign him help... my husband was...there to help me make sure that everything was carried through properly.”

Support Group

The participants who attended support groups found support for their role in terms of expert help about medications with associated information specific to the illness (PD), and support for emotional challenges, in addition to information about where to find equipment and services. One participant described the support group as a place to talk, learn, and share. One participant provided information to other caregivers about AI options to facilitate their role. Still another found friendship. All of the participants described a learning environment specific to their challenges, whether that was accepting their family member’s illness, where to find assistive devices, advice about preparing financially, and comparing stages of their family member’s illness progression.

P1: (Support group) is not something I have done. Since in-home PT, there has been a lot of difference.”

P2 had been to about four support group meetings. “I was... uncomfortable telling (mother) it was an Alzheimer’s support group. My brothers and their wives know.”

P3 had previous experience as a caregiver when his wife was ill, and although that included considerable conversation with his wife’s physician about her treatment, he says of his father’s doctors, “they gave me enough information to at least get started...so I started getting information from other caretakers...emotions get pretty rough at the

support group... It doesn't end at that; they have the recovery period, and that's what they are using this for... There are commonalities to watch for."

P4 felt similarly, "I think it is important that people understand what the circumstances are and what a support group does... I have been doing the support group for the last two years... (it) helped me tremendously... the person that heads the group... the other people you talk to in the group... prepared (me) for a lot of things that a lot of people, if you didn't ask for help or ask for support, would not know. It helped me tremendously to know what was coming and what was expected of me. ... I had to do this, or I had a problem with... wandering... speakers come in and talk to us... a lot of people... deny... the main thing is people who will support you, listen, and understand."

P5: "When I have questions, I go to the social worker at the support group and ask questions at the support group."

P6: "informal support groups... friends who have gone through the same thing or are going through the same thing."

P7: "We have been going to (the support group) pretty regularly for the last four years at least... to get ideas... to get to know people that are caregivers or who have PD... to socialize. (One) advantage of the support group... some... were in a more advanced stage."

P8: "As far as the caregiver role, I can't really say that I have gotten a lot of information... other than (from) the people... at the support group."

Theme 5: Caregivers may struggle to think of caregiver role as work.

Participants were asked how their experience at work compares to their experience in the healthcare transaction. The specificity of the question did not reduce the range of responses but responses appear to come from thinking about work. The second category, caregiver recommendations, is dominated by organization found in work processes. Table X provides a comparison of responses.

Caregiver Self-reports of Job/Work Terms.

P1 did not feel job training compared to learning to be a caregiver. However, she refers to having worked "as a team...hands-on," and uses terms like routine and being "on the same page." She describes evaluations, attention to detail, and triaging resources.

P2 said her nursing work experience gave her a perspective, "it wasn't like I had an unrealistic approach." She had worked in LTC, she said, "if she has to go to assisted living that's fine, it would be the best thing for her."

P3 and his wife researched brain cancer after she was diagnosed and communicated their findings with her doctors. His team experience included quality circles, "we experimented with new ways of creating teams to have the employees all feel ownership in solutions."

P4 had volunteered in the Seniors' Health Insurance Information Program (SHIIP), where he received training that "really helped me. He described training in work in terms of "cross-trained, discipline, regulations, and compliance." He admired a former boss who encouraged autonomy, "a great part of their success." He felt "there was kind

of a vacuum” between the time of his wife’s diagnosis and when he put his wife in a nursing home, “where it all started...then I learned a lot.”

P5 found differences between the organization of her caregiver role and a job “because this is a human person...not like a job.” However, when describing her documentation of her partner's day to day health, she says, "this is my job." In work, she says, “nobody ever really works alone... everybody is a contributor to the organization, so we are all a team member.” She described work as a series of lateral moves, in which one acquires more job skills, “just kind of move on to gradually get into that job.”

P6 believes she thinks about her role logically and would involve the doctor with what is happening, “let’s figure out a solution.” In her work experience, it was...typical working with teams, running teams, working with others to get projects done.” She says, “you know the questions to ask...I think I am more disciplined...being a manager...involved with a lot of projects makes me prepared to look at everything.”

P7 described leading in work and ways that he managed new leadership conflict, describing challenges that repeated and a rationale for action taken. He recalled relationships with management that were reciprocal, “most listened,” and accepting direction because “they had the authority,” while learning that “you could inform them of things that might change what they would tell you to do.” Training at work varied with the job, from 2-3 weeks to 6 weeks. His preference was for sufficient information, good manuals, laid out programs, and proper personnel.

P8's training in work included online coursework, manuals, a help desk, reading, orientation, shadowing, and mentoring. When asked about the information she received

for her caregiver role, she described the support group. "We find out things from other people. I can't really say that I have gotten a lot of information or sought a lot of information" from others. She was not able to compare information she may have received in the early days of her husband's diagnosis with the training she has received in work except to say, "just as we went through the years...we have just asked more questions and read some books, and that kind of thing."

P9 was an air force veteran who had experience with teams. She related that regarding her father's care, she "wanted to be part of the team...have some input" but noted there were times when they didn't "let me have input, like, when the door was closed." She felt training for even medical procedures was lacking, "they just told me where to put it (the injection), and that was it." She compared military discipline and leadership to her caregiving experience, "I...felt that I was in charge...and my husband was like the second."

Caregiver Recommendations

P1: "If I ever become an advocate...there are some things you need to watch for...because the doctor is not going to tell you ...get your ducks in a row, power of attorney...you cannot be over-detailed...have to stay on top of it and the people who are doing things...be patient, the biggest thing, they don't know what you are going through...the caregiver mental stress...and you don't know what they are going through...they see us come and go, get in a car and go...that is very depressing. I tell everyone...it is easier to let him know: I'm going to put your shoes on."

P3 does not feel hospice rules adequately address Alzheimer's at all.

"Alzheimer's is not a car accident that happens immediately. Even brain cancer, 2-4 years, is a long time. I would like to see teams of care that know this is going to be at least a 2 ½ -5-year process, that this has to be done, this has to be done, this has to be done. There are going to be...variations, but I don't see the proper application of our knowledge toward how we are actually doing things."

P4 said, "early on, there could have been more information...because you get to that denial situation. I mentioned this one person who is in total denial. And I was too until I realized that you cannot deny it is going to happen. That little zone in there when you think it is not going to happen, that you have to get over."

P5 said a book she got from the hospital helped her organize..."one section of the doctor's appointments, one section of meds" She described her progression...last month, I just started journaling...because the book just had two lines...wasn't what I needed anymore...we went for Alzheimer's checkup...there wasn't enough room to write that...so I have organized like that."

P6 values the long-term relationship she has with her family physician and appreciates how it would be if she didn't have that. "the medical profession is just growing and growing and their focus is to just get them out. That happened with my eye doctor who passed away. He would spend so much time with you, he was the only one who would see you and I went to this massive office where 50 people would see you before you saw the doctor and you only see him one minute."

P7 acknowledges that healthcare interventions on his wife's behalf had a benefit for him, but he could not recall that healthcare provided much in the way of help for his caregiver role specifically. "I don't know what would help out. The more people you can get to know, the more advice you get, sometimes you get too much, you don't know which to start out but you figure which fits you."

P8 said, "My experience with healthcare is primarily positive but I feel strongly that patients and caregivers do have to make choices about the professionals they see and put their trust in."

P9 said her experience as a caregiver was "risky...trying to make sure everything was carried out the way it was supposed to be...and not knowing whether or not you were doing it correctly." She thought that healthcare appreciated (them) but was not sure they understood her role, "they never talked to me about it. I hope they did."

Table 6

Comparisons of Work Experience and Experience in Doctor's Office

-
1. Does not compare but mentions numerous work terms
 2. Having worked in healthcare provides perspective
 3. Incorporated research experience into interactions with HC
 4. SHIP training was instrumental in his financial adjustment
 5. Differences between caregiving and work are human
 6. Work experience influences logical approach to caregiving
 7. Cited preferences for information in work and leading
 8. Specific work preferences, vague on caregiving process
 9. Healthcare team was not on par with military team experience
-

Table 7

Participant Recommendations

-
1. Advocacy, attention to detail, dealing with stress
-

-
2. Criticism of hospice rules, applicability to AD
 3. More information early to avoid denial
 4. Tool to organize elements of caregiving
 5. Laments loss of one on one time
 6. HC assistance with wife not specific to caregiving role
 7. Too much advice can be a bad thing
 8. Caregivers must make informed choices they trust
 9. Caregiver is risky, not enough information
 10. Appreciated but not necessarily understood
-

Summary

This study approaches the central research question of why family caregivers report non-supportive interaction in the healthcare transaction, by examining three additional research questions. The first explores how much control the caregiver has in the healthcare transaction in terms of interview questions that asked participants about the origins of their caregiving roles. Elements of the interview questions included the nature of their relationship with their family members and reasons for assuming their caregiving roles, what they knew about caregiving, and their feelings about caregiving, including worries, commitment, and providence. Participant responses resulted in the first theme: Caregiver readiness for the caregiving role.

The second research question was: Does the caregiver feel healthcare values his participation in the healthcare transaction? Some variance in expectations was evident by participant remarks about expectations of their interaction with healthcare. Questions explored the presence and influence of the Advance directive. Also, participants reflected on their expectations of healthcare, their perception of leadership by healthcare, their leadership experience in work, personal experience with teams, and thoughts about

whether they were acting as a team with healthcare. The theme that resulted was healthcare support for the caregiver role.

The third research question was: Do caregivers view healthcare as providing leadership? Data mined from interview questions described how participants do new things, how they get information, kinds of information they have received, and their experience with communication. Some responses seemed to be heuristically grounded, while others were specific to a schema, such as for work. The result of this inquiry was the third theme, evidence of ambiguity in the caregiver role.

Data analysis resulted in two emerging themes not specific to the research questions. Recruitment of the majority of participants was from support group meetings, and this produced data for Theme 4: Support. This theme reports caregiver remarks about help from healthcare, from the caregiver's team, and support groups. The data reflects the support that is specific to the caregiver role. Related interview questions include those exploring assistance from healthcare, healthcare understanding/empathy of/for reasons for caregiving; ways healthcare has demonstrated support, and the family team's help.

Theme 5: Caregivers may struggle to think of the caregiver role as work, is also an emergent theme. Multiple interview questions probing the participant's work experience on topics of obtaining information on a job, work experience, job training, teams, etc., produced data contributing to this theme.

Chapter 5 presents the interpretation of the findings, limitations of the study, recommendations for further research, social implications of the findings, and the study conclusions.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

Chapter 5 revisits the nature and purpose of the study and reasons why it is important, along with a summary and interpretation of the findings. Social implications, limitations of the study and recommendations for future research follow, ending with the study's overall conclusion.

The effort to understand the family caregiver and be of assistance to the family caregiver role is now some 50 years in progress. What we know is the research sees the family caregiver as an essential worker, and considerable is known about what the family caregiver is telling us are basic needs. This paper contributes to the body of knowledge about the family caregiver by introducing the concept of the caregiver performing a role that can be understood in terms of work adjustment.

Nature and Purpose of the Study

The purpose of this study was to examine the family caregiver experience in the healthcare transaction from a work construct, to gain more understanding for caregiver reports of non-supportive interaction. The family caregiver phenomenon has garnered considerable attention in especially the last decade, about issues of caregiving challenges and associated burden. The TWA construct allows the presumption that caregiver reports of non-supportive interaction are indicators of dissatisfaction that can be understood in the context of worker dissatisfaction.

This study used a qualitative phenomenological design to explore the experience of the family caregiver in the healthcare transaction. Data obtained from semi-structured

interviews with a purposeful sample of nine participants, provided insight into meaning participants ascribed to their caregiving roles, their interaction with healthcare providers, their experience with training in a job and for their caregiving roles, their experience with teams and leadership in work and in the healthcare transaction, and their recommendations for the caregiving dynamic. The theoretical construct chosen for this study was TWA with a goal of anchoring the caregiver perceptions, adjustment, and responses related to their caregiving role to a model that successfully predicts an employee response to the work environment.

The central research question of this study asked why family caregivers report non-supportive interaction in the healthcare transaction. Three additional questions formed the basis of the semi-structured interview:

1. How much control does the caregiver have in the healthcare transaction?
2. Does the caregiver feel valued in the healthcare transaction?
3. Do caregivers view the healthcare provider as providing leadership?

The main findings of this study included that the participants were not prepared for caregiving, but that they found responsible and organized ways to meet challenges. The advance directive did not appear to impact participant decisions in this study, however, while participants appreciated and wanted information from healthcare about their family members' health, they did not rely on healthcare for information about their caregiving roles. TWA was a useful framework by which to evaluate how participants adjusted to inadequate information about their caregiving roles and the participants' response to that deficiency. The introduction of discussion about work related terms and

concepts, such as training, leadership, and team, seemed to facilitate the participants discussion about elements of their process and establish a method of communication that was less vague than reciting feelings. These findings are discussed in more detail in the interpretation of findings section that follows.

Interpretation of the Findings

Findings indicate that caregivers come unprepared to their roles, and caregivers experience confusion, disorientation, and frustration in the early days of their roles. The emergence of the caregiving role for participants in this study occurred by various degrees of awareness that the family member's health was changing, characterized by behavior typical of normal family interaction. As their situations progressed, participants remained focused on their relationship with the family member while exploring options for organizing their responses to caregiving challenges. Various factors were reported for decisions to assume a caregiving role including availability, commitment to keeping family member at home, understanding of the disease trajectory, and feelings about ability to deliver the best quality care. Relationship with the family member factored strongly in all participants' decisions to assume a caregiving role. However, participants reported having little or no certainty about what their caregiving roles would entail and a desire to learn about that aspect. While all participants indicated either a desire to maintain their family members' independence as long as possible or keep them in the home for the duration of their illness, more than half indicated LTC was an eventuality.

A considerable range of responses about expectations of healthcare indicates the caregiver's role in the healthcare transaction is ambiguous and not informed by the

Advance directive. The presence of an Advance directive did not appear to influence the caregiver's perception of healthcare's obligation to provide information supportive of their caregiving role. The data does not specifically explain whether the participants understand the purpose of the Advance directive, but two had no Advance directive in place. On the other hand, participants did not report high expectations that healthcare would be a major source of information about their caregiving roles. Specifically, the participants seemed to separate their roles as personal, not part of the healthcare transaction, which was about their family members' healthcare. Additionally, while some participants reported occasions when they pressed healthcare for specific information or rejected information based for reasons such as relevance to current need, the majority indicated that the modern healthcare environment is not one that is conducive to extensive conversation, lowering their expectation that they would communicate about aspects of their roles.

The findings in this study indicate participants' response to the non-supportive aspect of their caregiving roles in interaction with healthcare was to explore other options for information and support. This finding affirms previous research findings that caregivers find inadequate support for their roles in the healthcare transaction. It is also supportive of evidence related to TWA, and disengagement theory. The caregiver utilizing an engagement strategy actively strives to manage the caregiving challenge with change (Garcia-Alberca et al., 2012). Conversely, disengagement strategies simulate withdrawal from the challenge interaction (Garcia-Alberca et al., 2012).

According to TWA, worker adaption in the challenge of fit in the environment is reactive or active in regard to challenges. The reactive response involves change to the person, while the active response focuses on change to the environment. Participants in this study demonstrated a reactive response by taking responsibility for the interpersonal aspect of the healthcare transaction. They exhibited a strong desire to preserve their relationships with their family members' healthcare providers by refraining from criticism or negative comments, rationalizing modern interaction in the healthcare environment, and focusing on the importance of healthcare as an essential resource in their family member's health. The participants' active response to lack of information was to explore services on their own, join a support group, and/or consult among other caregivers.

Disengagement may also occur as a way to change one's attachment to existing problem-solving strategies if that method interferes with primary objectives or to overcome disparities when the individual recognizes resources available from the work environment are out of synch with personal requirements (Niessen, Binnewies, & Rank, 2010). TWA characterizes this type of response as adaptive (Dawis & Lofquist, 1984). If these participants had expectations about training from their employment experience, they abandoned them for more efficacious strategies. Further, just as the caregivers' understanding of their roles in the family shifts with changes to the family members' health, so does their understanding of their roles in the healthcare transaction. Ultimately, the caregiver adjusts his role identity or changes his behavior to meet the change challenge and/or seeks alternatives to decrease the need (Montgomery & Kosloski, 2009).

Participants in this study did not communicate powerlessness or demonstrate helplessness. The participants' reports of resignation to low support for their role from HC, expectations for possible help with their role from HC, and personal motivation to meet the challenge of caring for their family members, operated in tandem to evidence that learning was not diminished. While the participants did report little or no support for their caregiving role, their response to the non-supportive aspect of their caregiving roles in interaction with healthcare was to disengage to alternative options for information and support. Motivation for their caregiving roles appeared to derive from commitment to the family member and to an optimum outcome for the family member. None of the participants indicated that lack of support for their caregiving role influenced their commitment to their roles. Instead, while the individual responses of each participant differ in some ways, all reflect confidence in their ability to manage their roles, evidencing strong self-efficacy supported by thoughts about their objectives in achieving their goals. Many spoke of their roles as providential, which appeared to contribute strength to their commitment, but also reflected a willingness to be positive when circumstances were less than optimistic. All participants advocated for their family members and were not deterred by obstacles of lack of information in the healthcare transaction.

Burnout in participants of this study appeared to be a function of the level of care participants performed. One participant who reported burnout was unique among the other participants to the extent that her caregiving involved heavy cares, primarily transfers, from the beginning of her caregiving career. Experience in ancillary healthcare

roles directed her pursuit of financial support, durable medical equipment, and auxiliary home staffing. Progress on that front at the time of a follow-up interview included substantially increased home health support and additional durable medical equipment and, with local help, the purchase of a wheelchair van. This participant and four other participants all communicated that they had considered LTC for when the time came when they were no longer able to manage heavier cares, those four other participants were all attending support groups. One participant who reported LTC would never be an option, did not attend a support group but had many friends who supported her. The live-in help she hired was referred by one of those friends.

The chief agency of organized support for caregivers in this study were the caregiver support group and the support group but not altogether. Three participants did not participate in a formal support group, and all of these three did not express the need for one. Of them, two, and one other, reported accessing previous and current knowledge gained by employment in healthcare that enabled them to network and/or make decisions based on personal healthcare expertise. Two participants (one who attended a support group and one who did not) reported in terms of established schemas for strategic thinking gained from management experience and team experience. The significance of teamwork was important to all participants, and expressed in terms of the family team as well as the family member healthcare team. While participants deferred to the physician on health specifics, they asserted a leadership role in aspects of decision making and the general welfare of their family members.

A previous study found male caregivers wanted information that enabled orientation to the caregiver role and decision making, details about their family members' conditions, and assistance with accessing useful resources (Neufeld & Eastlick, 2009). A study of female caregivers defined non-supportive interaction as those responses by healthcare that undermine credibility, are ineffective, or fall short of expectations, regardless of intentions (Neufeld, Harrison, Stewart, & Hughes (2008). While participants in this study did not report personal affronts by healthcare to any extent, all participants cited lack of information and orientation to their roles as significant. It could be inferred from what most participants reported that while they felt included in the triad, they did not feel either essential or expert. While participants did cite healthcare as having provided useful information about caring for their family member that ultimately contributed to their role knowledge, only one reported praise by healthcare, and none reported feelings that they were appreciated as necessary to any particular part of the healthcare transaction. The participants expounded on elements of their interaction that they felt were important communication about their family members' health, and that contributed to their understanding of their family members' health. While some participants recognized healthcare willingness to accommodate them, none expressed any confidence that those exchanges were valued by healthcare.

The last finding in this study introduces a dynamic that appears to bridge the healthcare impulse to doctor the caregiver and the caregivers' instincts to manage their roles. Some findings are key to developing the premise that caregiver dissatisfaction stems from an inability to access information. This finding demonstrates that the work

role context may be one that helps the caregiver organize his role around something familiar, which in turn, enables a conversation and improves the caregiver ability to formulate questions.

Participants in this study struggled to define their processes and purposes in their caregiving roles. There was a marked difference in confidence of responses when participants were asked about their work or job experience. Although the study handout explains that the study concerns work adjustment and family caregiver engagement in the healthcare transaction, participants initially struggled to shift to discussing elements of their work experience. Once they adjusted to the topic, they came to speak of work easily and they were able to conceptualize work concepts like training, evaluations, leaders, teams, information and resources, as dynamics of their caregiving roles. As they proceeded, they confidently related work role dynamics to their caregiving roles and their roles in the healthcare transaction. This suggests that the participants benefited from a method of organizing thoughts that transformed them from the abstract to a known context. Using work processes, they have an improved ability to conceptualize themselves in their family member's healthcare team and critique the relationships they have with healthcare in terms of who the leaders are, when there is a leader, and what leadership they require and want to perform. They begin to translate tasks into performance, objectify goals, perceive needs, and evaluate their own strategy.

Social implications

Clarification of role dynamics and boundaries has the potential to moderate the caregiver frustration about the availability of information and enhance the caregiver role

in the healthcare transaction. Further, it may reduce the randomness of caregiver responses to caregiving challenges while improving the quality of the caregiver role and ultimately, support for the dependent family member.

The boundary in question in this study appears to be whether participation in the healthcare triad implies caregiver consent to healthcare inserting into the family relationship or the caregiver personal privacy. No participants reported an unsatisfactory experience of this nature. Only one participant reported any issue related to boundaries, which was when a physician they did not know approached her and her husband in a waiting room and attempted to give them information about PD. The impact of unclear boundaries might contribute to the dissatisfaction Neufeld, Harrison, Stewart, & Hughes (2008) reported, that created issues of credibility and disappointment with healthcare responses. In short, when the objectives of healthcare and the caregiver are not aligned, there is greater potential for failed communication.

Informing caregivers of resources available when they first present, when the healthcare dyad first becomes a triad, is an acknowledgement of the caregiver role, establishing a means to communicate about the caregiving challenge. It will significantly reduce the phenomenon of every new caregiver having to start their caregiving careers from scratch. It may also inform policy that enables improved support for the family caregiver role and enhances the caregiver role in the healthcare transaction.

Limitations of the Study

A main limitation of this study is it only briefly explores the caregiver expectation of healthcare in terms of information provided. It does not provide much information

about participant feelings about healthcare involvement with the family role or the caregiver role or what, if any expectations, participants have about overriding authority in the healthcare transaction as it relates to the caregiving role. An implied relationship exists simply when an agreed upon appointment is kept. Other elements of the relationship between a doctor and a patient that are implied, may be inferred by the Advance directive to extend to the caregiver. As a decision maker for the family member, the caregiver may seek information pertinent to the execution of their caregiving roles. However, it is not clear if the caregiver relationship with the healthcare provider extends to healthcare acting as a mentor for the caregiving role and/or whether healthcare has responsibility for caregiver health or well-being. Further, this study does not explore the extent to which the participants want healthcare interventions into personal and/or professional (caregiving role) areas.

From the perspective that the family caregiver in the healthcare transaction is a worker, we have something of an anomaly that invites many questions. The Advance directive and HIPPA guide empowerment and privacy of the patient, but may not clearly identify personal parameters of a caregiver. Implied consent by a family member for healthcare intervention may not be appropriate for a designated caregiver acting in a work role. Participants in this study seem to isolate the caregiver role from the healthcare triad. Future study might reveal whether this is a function of a desire to preserve autonomy or an additional consequence of the ambiguous nature of the caregiver in the healthcare triad.

It is clear, from the results of this study and others in the literature, that the caregiving role can be complex. In all other areas of work, some organized structure oversees the development of the work processes. The participants in this study and in others (Neufeld et al., 2008; Neufeld & Eastlick Kushner, 2009) consistently identify lack of information as a concern, especially in the early days of their roles. In this sense, it can be assumed that without guiding resources, each new caregiver is thrust into a process for which they must invent solutions and that caregiver approaches to the problem of organizing their roles varies widely. The obvious shift in participant's confidence for discussion of known work terms indicates a need to identify elements of the caregiving role that are ambiguous and develop a way to inform those elements in language that is also common.

In that sense, there is a need to explore that relationship further, as healthcare moves toward assessing the needs of the caregiver, to learn about parameters and personal boundaries the caregiver may have and what is most efficacious to the caregiver role.

The findings in this study point to utilizing work adjustment as a foundation for understanding what the caregiver needs and how the caregiver responds to challenges of the caregiving role. More important, the findings demonstrate that in a known context, caregivers become articulate about dynamics of their roles in ways that would be immediately understandable across disciplines. Thus, there is support for future research specific to the working relationship of the family caregiver with healthcare. Specifically, whether the caregiver in a healthcare transaction is viewed as equal to the task of the

caregiving role and if it is possible for the caregiver to manage their roles independently given adequate information. This study is limited for this concept because it did not explore the participant feelings about healthcare involvement with their family role or their family caregiver role or the idea of any overriding authority in the healthcare/patient/caregiver triad.

While the literature provides explanation for dynamics and expectations of the professional/patient dyad, the triad created by the emergence of a caregiver, is less clear. Various authors have discussed how healthcare accommodates/facilitates the caregiver in the triad, with emphasis on identifying caregiver needs, partnering with caregivers to, in part, merge the caregiver viewpoint with the practitioner viewpoint, and the effect of practitioner methods for communicating with caregivers, and caregiver expectations of the practitioner on the outcome of a successful triad (Cheraghi-Sohi et al., 2008, Funk, Stajduhar & Cloutier-Fisher, 2010, Levesque et al 2010).

At this time, the field of study into the family caregiver is broadening to embrace a stronger healthcare role that includes assessment of family caregiver needs. It is driven, in part, by ways to address healthcare roles in the family caregiver burden realm that include actual coded (CPT, ICD-10) and billable responses (National Academies, 2016). This opens the door for healthcare-initiated assessments of family caregiver needs that lead to useful interventions and potential Medicare reimbursements. The contradictions of these dynamics and what appears to be a strong autonomous response in the participants of this study, expose a need for more exploration of the caregiver perspective.

In chapter 2 TWA describes the processes of perceiving and responding to a particular situation. The observer and observed must agree on the problem to begin finding an appropriate or useful solution to the problem. In this study, I propose that healthcare perceives and responds to a different problem than caregivers report as the basis of their frustration. Healthcare sees the burdened caregiver and the caregiver sees healthcare's pill as non-effective. The caregiver in this study and others is asking for tools and resources to perform their roles and healthcare interprets their complaint as a symptom of something else, such as stress. This study proposes that the problem might be considerably reduced with the introduction of a work framework that prescribes ways to achieve work goals. Further, the normal organizational response to achieving correspondence is not available in the caregiver/healthcare transaction without some agreement on the definition of the caregiver. This study attempts to bring work dynamics into the equation to understand the caregiver better. Further study should examine the organizational response to this unique worker role.

Last, participants in this study were primarily people aged 50 or older who all had work experience. While access to orienting information would seem to have benefit across age differences, a new, young parent with no work experience may have a different response to a work adjustment methodology. However, it can also be said that a system of orientation will benefit a broad range of caregivers and be accepted by caregivers with little or no work experience, simply because it provides a starting point for an otherwise ambiguous challenge. Further research into this dynamic could isolate specific elements of adjustment by age and experience.

Recommendations for Practice

For some time now, information has been a major deficiency reported by family caregivers. In *Families Caring for an Aging America* (2016), we have an account of the family caregiver dynamics from the healthcare provider viewpoint, which includes known elements of a caregiver role. Yet, the caregivers in this study did not report direction by healthcare to caregiving support resources. The results of this study show that the family caregiver is not prepared for the challenges of the caregiving role. Much of the information these participants reported using, developed over a period of time characterized by uncertainty, is precisely what is provided by the *Families* (2016) report, and could be overcome if healthcare were to provide at least, a list of resources, handed out when the family caregiver first appears with the patient. This orientation would include local resources and websites about the family caregiving role and organizations of support for specific diseases and disorders.

In 2016, the National Academies of Sciences, Engineering, and Medicine published a comprehensive report: *Families Caring for an Aging America*. Among the contents are details of the family caregiving phenomenon in the United States including who is a caregiver, dynamics and impact of caregiving roles, economics of caregiving, programs of support including assessments, technological impacts, interventions, policy, etc., the family caregiver interaction with healthcare, and recommendations to alleviate the urgent challenges of caregiving. While the authors cite extensive and legitimate barriers to optimizing the healthcare/caregiver interaction and healthcare's role in assisting the caregiver, the impact of what is known and reported by the authors seems to

sit and wait for new action. In other words, it is noted numerous times in the literature and in the National Academies (2016) report that caregivers want information, the nature of which is identified in the report.

To illustrate, Table 5-1 (National Academies, 2016) lists eight known caregiver interventions, acknowledging implementation sites. For example, for skills care, there are 20 known home care agencies, and occupational therapists covered by Medicare. Another is the savvy caregiver, for which the table mentions training for caregivers of people with dementia. The table gives a little information about available training sites but participants in this study found support groups administered by local chapters of the Alzheimer's Association (2020), on their own.

The introduction of a family member to the healthcare dyad is the first indicator for healthcare of the family's perceived need for a caregiver, and by association, the opportunity for healthcare to get involved with the family caregiver. Initial involvement, according to the findings of this and other studies, might be as simple as an informational document listing options for support in the community, and recommendations or suggestions for websites that are specific to the caregiving role, sites that inform users about dynamics of a disease, skills for caring for a family member with a disease, services commonly used by family caregivers, and other generally approved support mechanisms. In this study as in others, the caregiver stories reveal a consistent pattern of onset of the caregiver career with the associated overwhelmed feelings, lack of information leading to investigation of information options, and gradual increase of confidence for the caregiving role with the acquisition of information. There is potential

to substantially modify this pattern if healthcare acts as a distributor of known information suitable for lay consumption at the moment the caregiver presents to the healthcare dyad transaction. Further, by introducing information early, healthcare facilitates a means for the caregiver to organize his perception of the caregiving role and begin conceptualizing not only needs and solutions, but a way to have a dialogue about the caregiving role, skipping the arduous process of learning that until now, most caregivers have attempted on their own.

Specifically, federal websites such as the Centers for Medicare & Medicaid Services (CMS), <https://www.cms.gov/>, the U.S. Department of Health and Human Services (HHS), <https://www.hhs.gov/>, and National Institutes of Health (NIH), provide links to each other and other expansive resources to facilitate the caregiving role. Information ranges from simple and basic to comprehensive as with the NIH National Library of Medicine MedlinePlus webpage, https://medlineplus.gov, where consumers can access a page specific to caregivers: <https://medlineplus.gov/caregivers>.

The appearance of a family member in the appointment with the family physician, should serve as an important trigger for healthcare to acknowledge the presence of a caregiver. This is strategic to facilitating the caregiver role. A simple handout (see Appendix E) with a recommendation and encouragement to the caregiver to explore the above resources at least, can serve as the beginning of the practitioner/caregiver relationship and serve as a basis for further dialogue in the triad.

Conclusion

The results of this study indicate (1) that caregivers are not prepared for a caregiving role, (2) that caregivers do not find HC actively motivated to assist with the caregiving role, (3) that caregivers actively seek resolution for the ambiguity of their roles outside the HC transaction and (4) appreciate organized information when they find it, and (5) that the caregiver's account of caregiving lacks the organization typical of working roles, but (6) when work concepts enter the discussion, caregivers quickly apply them to their caregiving roles.

The introduction of work adjustment as a way of understanding what is missing in the analysis of the caregiver burden, may substantially reduce the need to think of caregivers as needy. To the contrary, the results of this study indicate caregivers are resilient and resourceful in their efforts to overcome the ambiguity of their roles, and that the introduction of a work framework had a strong effect on their ability to articulate circumstances that they otherwise struggled to define. Further, this study affirms the extensive evidence in previous research that caregivers are consistently citing lack of information as a problem in managing their roles, a problem that does not have to persist with all the online resources available. Finally, this study reveals that there is a need to further define the caregiver and the caregiver role in the healthcare transaction from the standpoint of the caregiver as an individual contributing to a shared objective.

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Appendix A: Interview Questions

1. How did you become a caregiver?
2. What is your definition of a caregiver?
3. What did you think caregiving would be like?
4. Describe/define your caregiver role.
5. What training did you have for your caregiver role?
6. What kind of assistance with your caregiver role do you look for from healthcare?
7. What kind of assistance do you get from healthcare for your caregiver role?
8. Who do you consider the leader of your family member's healthcare team?
9. How do you communicate with the healthcare team?
10. In what way(s) do you feel a part of your family member's healthcare team?
11. Describe how you believe your family member feels about having you as a caregiver.
12. Is there a living will/durable power of attorney for healthcare?
 - a. Are you the designee?
 - b. Did you provide a copy of the medical POA to HC team?
13. What kind of work have you done in your life?
14. What is your experience as a trainee?
15. What sort of things do you expect when you are on a new job?
16. What is your team experience?
17. What qualities/traits do you look for in a supervisor or a leader?
18. Describe your experience as a leader/supervisor.

19. What would you do if you were in the middle of something new and realized you were not sure how to proceed, how would you go about getting assistance?
20. How does your experience at work compare to your experience in the doctor's office?
21. Is working with healthcare anything like your job?
22. How much do you think healthcare professionals understand your reasons for caregiving?
23. In what ways have healthcare professionals demonstrated understanding, empathy for your role?
24. In what ways have/do healthcare professionals support you in your effort?
25. What kind of leadership do you find in your family member's healthcare team?
26. Tell me about the kind of information and/or advice you have received from your family member's healthcare team.
27. What kind of end of life information have you received?
28. If you were to imagine training for a caregiver what would it be.

Appendix B: Letter to Professional Association

January 30, 2016

Dear _____

My name is Cynthia Uecker and I am a doctoral candidate at Walden University. I am conducting dissertation research on the experience of the family caregiver in the healthcare transaction. The caregiver is a much-researched population but little is understood about the caregiver as someone with expectations in the healthcare transaction that mimic work adjustment. This research will contribute to understanding the caregiver experience in terms of social cognition and schemas individuals create to understand their environment and formulate responses to their environments.

Your cooperation is very important to this research as you have contact with caregivers who bring their family members to your agency for respite. I am asking your assistance in identifying those individuals you know who might be interested in participating in this research. When you provide me with information about those individuals, I will contact them to talk about the nature of the study. They are free to choose to participate and can discontinue participation at any time. Any information provided by the participants is strictly confidential.

I would be so happy to hear from you. Please call me at [REDACTED] to discuss any questions you may have regarding this study and your role in identifying research participants.

Thank you for your consideration.

Cynthia J. Uecker

Doctoral Candidate

Walden University

Appendix C: Email to Participant

Dear _____:

This email is to follow up our conversation regarding your interest in participating in my doctoral study. I understand your time is valuable, and I sincerely appreciate your consideration. You will find two attachments to this email, the Consent Form and a Demographic Background Survey. After you have read the consent form, if you agree to participate, you will need to fill out the Background Survey.

You will indicate your consent by replying to this email. Please attach the completed Background Survey to your reply. If you choose, you may also copy the completed survey and paste it to your return email.

The interview will take approximately 1 ½ to 2 hours and will be recorded over the telephone. There is nothing about the interview that should make you uncomfortable and all information you provide is strictly confidential.

You do not have to respond if you are not interested in this study. If you do not respond, no one will contact you. If you have any questions about the consent form or the survey can be reached at _____ or you may email me at _____

Thank you again for your consideration.

Cynthia Uecker

Doctoral Candidate

Walden University

Appendix D: Demographic Survey

Thank you very much for your interest in this research. Your participation is much appreciated. Prior to the recorded interview, please complete the following questionnaire and email it as an attachment to [REDACTED]

Please indicate your age:

- 50-55 years old
- 56-60 years old
- 61-65 years old
- 66-70
- 71 years or older

Please indicate your marital status

- Single, never married
- Married or domestic partnership
- Widowed
- Divorced
- Separated

Your health: Do you have any disability?

- Yes
- No

If you answered that you are disabled please briefly describe your disability

Your caregiver career: How long have you been a caregiver?

- 1 year
- 2-3 years
- 4-5 years
- Other

What family member(s) are you caring for?

- Mother
- Father
- Grandparent
- Other _____

What kinds of tasks do you perform as a caregiver?

- Personal cares such as bathing
- Transportation
- Coordination of medical visits
- Daily household activities such as housekeeping and shopping
- Management of finances
- Coordination of medical care such as dispensing of medication and performance of medical treatments
- Communication with the medical team

- Provide companionship
- Provide emotional support
- Coordinate services

What agencies/organizations/healthcare providers do you work with as a caregiver? List all.

- Family member's physician (primary care provider), physical therapist or other professional _____
- Home Health agency
- Respite agency
- Hospice
- Other _____

Does your family member have an Advance directive? Yes No

Does your family member have a Durable Power of Attorney for Healthcare?

Yes No

Does your family member have a Living Will? Yes No

Education: What is the highest degree or level of school you have completed? *If currently enrolled, highest degree received.*

- No schooling completed
- Nursery school to 8th grade
- Some high school, no diploma
- High school graduate, diploma or the equivalent (for example: GED)
- Some college credit, no degree

- Trade/technical/vocational training
- Associate degree
- Bachelor's degree
- Master's degree
- Professional degree
- Doctorate degree

Are you currently employed full-time, part-time, not employed, or retired?

- full time
- part time
- not employed
- retired

Employer Type: Please describe your work

- Employee of a for-profit company or business or of an individual, for wages, salary, or commissions
- Employee of a not-for-profit, tax-exempt, or charitable organization
- Local government employee (city, county, etc.)
- State government employee
- Federal government employee
- Self-employed in own not-incorporated business, professional practice, or farm
- Self-employed in own incorporated business, professional practice, or farm
- Working without pay in family business or farm

What best describes your role in industry?

- Upper management
- Middle management
- Junior management
- Administrative staff
- Support staff
- Student
- Trained professional
- Skilled laborer
- Consultant
- Temporary employee
- Researcher
- Self-employed
- Other _____

The organization you work for is in which of the following:

- Public sector
- Private sector
- Not-for-profit
- Don't know
- Other _____

Indicate what type of industry you work in:

- Agriculture, Forestry, Fishing and Hunting
- Mining, Quarrying, and Oil and Gas Extraction

- Utilities
- Construction
- Manufacturing
- Wholesale Trade
- Retail Trade
- Transportation and Warehousing
- Information
- Finance and Insurance
- Real Estate and Rental and Leasing
- Professional, Scientific, and Technical Services
- Management of Companies and Enterprises
- Administrative and Support and Waste Management and Remediation Services
- Educational Services
- Health Care and Social Assistance
- Arts, Entertainment, and Recreation
- Accommodation and Food Services
- Other Services (except Public Administration)
- Public Administration

What sort of work teams have you participated in?

- Basic working team (i.e. member of a department such as mailroom, sales, accounting, etc.)
- Special team: (i.e. committee for example)

- Multi-functional team: (members from various departments formed for a short term or permanently)
- Self-directed team: (members share leadership and responsibility, for example, a band, design teams)
- Management team

Income: is your total annual income before taxes \$20,000 or more, or is it less than \$20,000?

- Under \$20,000
- Over \$20,000

Appendix E: Sample Handout

Caregiver Startup Information

You want to do all the right things for your loved one but it is a challenge to know where to start. Here are three Federal websites to get you started and you will find links to even more.



Start Learning now. Visit NOW

Centers for Medicare & Medicaid

<https://www.cms.gov/>

U.S. Department of Health and
Human Services

<https://www.hhs.gov/>

National Institutes of Health

<https://www.nih.gov/>

NIH National Library of Medicine
Medline Plus

<https://medlineplus.gov/>

