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EFFECTS OF ROLE REVERSAL BETWEEN PARENT AND ADULT OFFSPRING

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EFFECTS OF ROLE REVERSAL BETWEEN PARENT
AND ADULT OFFSPRING

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Daisy Zamorano
Antonio Quezada

May 2021

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ABSTRACT

The research study was conducted to gain a better understanding of the experiences of individuals who have undertaken the huge task of caring for a parent and therefore have experienced a role reversal. Research focused on the effects that caregiving has on caregivers, with an emphasis on how their role as caregivers impacts their mental, emotional, and physical health.

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Antonio Quezada:

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DEDICATION

To all those serving as caregivers, we hope that this research study can be utilized by social work practitioners and other providers to better serve you as you navigate the many challenges you encounter as you work to meet the needs of your loved ones.

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CHAPTER ONE

INTRODUCTION

Problem Formulation

Oftentimes, as parents get older and their health begins to decline the role of caregiver falls on the adult offspring. This occurrence leads to what is referred to as “parentification” or “role reversal,” a phenomenon defined by the exchange of family roles in which children or adolescents assume a caregiver or parenting role for their parents and/or siblings (Jurkovic, 1997). As highlighted in its definition, role reversal can occur at any given point during the lives of parent and offspring and may also include a child caring for a sibling. However, the research conducted in this research project focused on adult offspring as characterized by their age (18 and over) and care provided to parents and not siblings.

As adult offspring become the primary source of daily care for elderly and/or ill parents, they take on many of the day to day responsibilities once being performed by the parent. Fulfilling these newfound responsibilities and the reversal of roles can come at a tremendous expense to the caregiver’s leisure time, school activities or employment, (Abraham and Stein, 2012; Carton et al., 1998). Caregivers find themselves facing many challenges associated with the care they are now required to provide to their parents and it can have a damaging effect on not just their personal lives but also their physical and mental health (Gerain and Zech, 2019). Some of the aspects of caregivers’ lives

impacted by the stress that arises during role reversal can be but are not limited to academics, professional and personal life, health, and emotional well-being.

Given the relationships that are formed among caregivers and social workers as caregivers navigate the many challenges they face, it is vital to address how it is currently affecting the field of social work. As life expectancy continues to grow in the United States, with an average life expectancy of 78 years as of 2017 according to The World Bank (2019), so does the need for caregivers that can care for aging adults. This has a direct impact on the need for professionals with the ability to provide resources to caregivers and those being cared for. Social workers play an important role among these professionals. Oftentimes, social workers serve not only as service providers but also as a link to other services and as a result serve as a vital part of the caregiver/care recipient dyad. This creates the need for qualified and informed social workers who are able to meet the needs of this population.

Addressing the effects of role reversal among adult offspring as parents develop the need for care will contribute to the field of social work in multiple ways. For example, it will allow social workers involved with elderly or ill clients under the care of an adult offspring to be able to better understand the services needed by the family. In addition, it will equip social workers in clinical settings working with adult offspring caregivers who are experiencing the effects of role reversal with the opportunity to provide them with more adequate clinical

interventions. As a result, social workers will be able to improve the lives of both parents and the caregiving offspring.

Purpose of the Study

The purpose of this research study was to better understand the experiences of individuals who have undertaken the huge task of caring for a parent. Research focused on the effects that caregiving has on caregivers, with an emphasis on how their role as caregivers impacts their mental, emotional, and physical health. Existing research highlights the impact that caregiving often has on both the care recipient and provider but lacks information related to how a relationship, such as that of a parent being cared for by their adult offspring, affects an already stressful situation.

By employing the use of interviews to gather data reflecting the experiences of caregivers, this research study utilized a qualitative research method. This research design was used due to the researchers' need to gain a better understanding of the experiences of caregivers through the use of virtual interviews with social work practitioners who have experience working with this study's population of interest. As opposed to quantitative data, qualitative data allowed for researchers to collect narratives using interviews to better illustrate caregivers' experiences.

Significance of the Project for Social Work

Social workers play a major role in the lives of those they serve. The need to continue to improve the field of social work has led to research aimed at assessing the experiences of individuals who benefit from services provided by social workers. It was that same principle that inspired this research study, which aimed to better understand the experiences of caregivers in order to address their needs. By having conducted this research study, social workers and other providers will be able to provide a more holistic approach in assisting ill or elderly clients being cared for by their adult offspring.

In addition, this research study contributed to generalist social work practice by gathering information which can assist social workers working with caregivers during the engagement, assessment, and planning phases of services. By engaging caregivers caring for elderly or ill parents with a better understanding of the issues they face as caregivers and the effects of the role reversal they are experiencing, social workers can offer a more comprehensive assessment. As a result, social workers can assist caregivers in developing a plan that serves not just the care recipient but also addresses the needs of the caregiver.

The research question for this project was as follows: How does role reversal between parent and offspring affect the offspring (now caregiver)?

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter examines existing research related to the topics of caregiving and offspring serving as caregivers to parents. The subsections include defining a caregiver, prevalence of caregiving, financial impact, caregiver's health, and the research gaps and limitations. The final subsection examines the Caregiving Stress and Burden Model and The Job Demands- Resources Model, that are relevant to the population researched.

Defining a Caregiver

According to the American Psychological Association (APA), caregivers operate as home-based "care coordinators" as extensions of the care recipient's health care systems. With the cost of health care on the rise, individuals facing physical, mental or behavioral challenges most often seek family for caregiving needs. To ensure care recipients adhere to care needs, caregivers perform complex medical and/or daily living tasks (APA, 2019).

Formal and Informal Caregiver

As defined by the National Center on Caregiving, formal caregivers are those who provide care services in care settings such as childcare, residential care facilities, long-term care locations, or a patient's home with a paid salary. On the other hand, an informal caregiver is often characterized as being a family

member or other individual involved in assisting a care recipient with needs ranging from daily living activities to medical tasks and with no pay. This research project will focused on informal caregivers.

Caregiving Task. Caregivers help care recipients with activities of daily living (ADLs) that include but are not limited to tasks such as: dressing and undressing, getting in and out of bed, personal hygiene, or instrumental activities of daily living (IADLs) such as taking prescribed medications, transportation, help with the use of technology, and/or shopping for groceries (Family Caregiver Alliance, 2016). In addition to ADLs & IADLs, caregivers also assist in medical/nursing tasks such as: tube feedings, colostomy care, catheter, injections, among other complex care responsibilities (National Alliance on Caregiving, 2015). Other important tasks completed by caregivers include collaborating with multiple service providers, organizations, and other professionals on behalf of the patient. As well as monitoring the circumstances surrounding the patient's well-being and assessing for needed adjustments in care, and often act as an advocate for the care recipient with care providers, insurance agencies or community services (National Alliance on Caregiving, 2015). In comparison to other care providers such as those who care for other relatives or nonrelatives, those who care for parents spend 74% of their caregiving monitoring the health of their parent, 70% communicating with healthcare professionals, and 57% advocating with providers, services, and agencies (National Alliance on Caregiving, 2015).

Caregiver's Health

Caregivers are at risk of physical health problems, emotional and mental distress when complicated caregiving situations arise. Twenty-two percent of caregivers report having noticed a decline in their health as a result of caretaking (National Alliance on Caregiving, 2015). High levels of physical strain is felt among one in five caregivers, and two out of five view caregiving as emotionally stressful (National Alliance on Caregiving, 2015). Family caregivers to older relatives or friends appear to suffer higher levels of stress, depression, anxiety, and other mental health effects compared to their non-caregiving counterparts (Family Caregiver Alliance, 2006). Major depression is diagnosed within a fourth to one half of caregivers, and 40-70% with significant symptoms of depression (Zarit, S. 2006). As care recipient's functional status declines, depression and perceived burden increases for caregiver (Grunfeld, E. 2004).

Caregivers diagnosed with depression tend to suffer from coexisting disorders, such as substance abuse, anxiety, chronic illness and describe feelings of anger, frustration, helplessness, or guilt as a result of providing care (Center on Aging Society, 2005). Caregivers can also experience constant worry, a decrease in self-esteem, loss of self-identity or of uncertainty and less control of their lives than non-caregivers (Center on Aging Society, 2005 & Pinquart, M. & Sorensen, S. 2003). Female caregivers that comprise an average of 66% of all unpaid caregivers are at the expense of far worse higher levels of anxiety, depression and declining physical health than their male caregiver counterparts

(Family Caregiver Alliance, 2006). Due to increased stress, there has been an increase in prescription and psychotropic drug use by caregivers surpassing the use of non-caregivers and greater risk of displaying aggressive behaviors than others (Marks, N. Lambert, J.D., & Choi, H., 2002).

In comparison to non-caregivers, caregivers are at higher risk of: high blood pressure, heart attacks, heart disease, diabetes, arthritis, physical ailments such as headaches, acid reflux, bodily pain, obesity, diminished immune response, frequent infections and increased risk of cancers. This is part due to the added stress of and the lack of the caregiver's behalf to engage in health behaviors due to lack of energy and time to invest in themselves (Family Caregiver Alliance, 2006) .From the National Alliance on Caregiving (2015) report, 44% of caregivers expressed that caring for a parent is more emotionally stressful than caring for any other relative. Twenty-five percent of caregivers caring for a parent reported their own health to be worse from caregiving. Nearly 50% of caregivers find their role emotionally draining, and 38% consider their caregiving situation to be highly stressful. For those caregivers caring for a parent, the National Alliance on Caregiving (2015) report 57% had "no choice" of being a caregiver or not, due to feelings of "obligation". Younger caregivers have more at risk in addition to mental and physical health effects. Young caregivers often put schooling on hold or experience disruptions to their education, or drop out entirely, which then in return can impact their future career and earnings (National Alliance on Caregiving, 2005).

Research Gaps and Limitations

There is insufficient research that is targeted directly and specifically on the effects of role reversal between parent and offspring and how it affects the offspring now caregiver. The problem begins with scant research that targets specifically caregivers who are offspring of care recipient. Therefore, this study reviewed research on caregiving focusing on effects from caregiving, with an attempt to target caregivers who are offspring of care recipient.

Many effects of caregiving were found in the literature: high levels of physical strain, emotional stress, chronic disease, substance abuse or dependence, anxiety disorders, feelings of frustration, anger, guilt, helplessness, lower levels of self-esteem, loss of self-identity, feelings of uncertainty and less control of their lives, even financial problems, but what is unclear is how this is all complicated when the caregiver is the offspring- the gap in literature. There are gaps in specific subset of populations among caregivers who are offspring of care recipient, along with detailed information in dollars of the financial burden these individuals experience, and exact numbers that represent how many of these specific individuals are diagnosed with illnesses brought on by caregiving.

Among the limitations of this research project is the ability to locate participants based on existing records since offspring caring for a parent often go unpaid. Caregiving alone is not exhaustive in the effects caregivers experience, other factors and tasks can contribute to the negative effects experienced, making other factors and tasks limitations to this study.

Theories Guiding Conceptualization

Past research regarding caregiver burnout has solicited models such as the Model of Caregiving Stress and Burden, which emphasizes on stress as a result of caregiving, and The Job Demands-Resources Model, which introduces caregiver burnout as a two-dimensional process consisting of demands and resources (Gerain and Zech, 2019). However, both models fail to address other aspects surrounding caregiver burnout such as caregiver psychological or social factors and caregiver's characteristics. This research study employed The Informal Caregiving Integrative Model (ICIM), a theoretical framework introduced by Gerain and Zech as a model to guide future research such as this one. The ICIM provides a three-dimensional framework for studying informal caregiving that aims to take all aspects surrounding caregiver burnout under consideration, unlike other models have done before. This research study analyzed caregiver characteristics as defined by sociodemographic, psychological factors and physical state. As suggested by the ICIM, all aspects of a caregiver's life must be considered to determine how these factors put them at risk of caregiver burnout. Understanding the risk factors that can lead to caregiver burnout allowed researchers to use this theoretical model to guide this study.

Summary

This study examined how role reversal between parent and adult offspring affect the offspring as a result of caregiving. As some adult offspring become the primary source of care for elderly and/or ill parents, the reversal of roles can

come at a tremendous expense to the caregiver's mental, emotional, and physical health. To better understand the experiences of these individuals who undertake caring for a parent the use of the Caregiving Stress and Burden and The Job Demands- Resources models were utilized. The findings of this research can help social work professionals by improving their ability to provide adequate resources to not just their clients in need, but also for those serving as caregivers to those clients.

CHAPTER THREE

METHODS

Introduction

This study examines existing research related to the topic of caregiving and the effects of role reversal among offspring who are currently serving as caregivers to a parent. In this chapter, all components of how this study was conducted is discussed. The sections discussed include study design, sampling, data collection and instruments, procedures, protection of human subjects, and data analysis.

Study Design

For the purpose of this research project, the study design to best address the problem presented was a qualitative design. With the use of an exploratory method, social work practitioners who had experience working with caregivers that are offspring to their care recipients were interviewed. The use of open-ended exploratory questions gave interviewees the opportunity to provide researchers with qualitative data through their given responses. Previous research on caregiving has focused on the general effects from caretaking. The data findings of the interviews conducted by the researchers expanded on previous research regarding caregiving and the effects of role reversal between parent and offspring and its effects on the offspring as a caregiver.

As with any study design, the use of interviews will have limitations.

Limitations to using interviews to conduct research is that interviews are costly in time and impractical with large numbers of respondents. In addition, the quality of data depends upon the quality of the interaction which means interviews present the risk of the researcher introducing his or her bias. This could potentially result in the interviewee feeling uncomfortable to answer with complete honesty or to withhold information since interviews are less anonymous.

Sampling

This research study used a snowball design to gather participants and obtain data with a goal of 6 to 8 interviews to be conducted with social work practitioners who had experience working with this study's population of interest. Due to the COVID-19 pandemic and in an effort to adhere to social distancing regulations, researchers conducted interviews via Zoom meetings. Interviews were conducted at the convenience of the interviewee's date, time and location during the 2020 Fall Semester.

Social work practitioners were selected based on researcher's existing professional relationships with interview participants. In addition, other interview participants were gathered through a referral process as provided by the initial interviewees based on their existing professional relationships. "Social work practitioner" eligibility was identified based on their current or past experience working with the population being studied within the field of social work at a

licensed or MSW level. For the purpose of this study, "caregiving to a parent" was defined as an adult offspring taking care of an ill or aging parent.

Data Collection and Instruments

The interviews were conducted via Zoom by a mutually arranged date and time according to interviewee's availability. Interviews were audio-recorded with the consent of interviewee. Each interview began with a description of the study and its purpose followed by collection of demographic information. Demographic information gathered consisted of age, gender identification, ethnicity identification, achieved education level, employment title, and years of experience in the field of social work.

The independent variable for this study consisted of the relation to care recipient, represented by the values: offspring, other. The dependent variable was the effects reported by offspring as a result of providing care to a parent. A series of open-ended questions to assess the effects of caregiving and role reversal on caregivers were asked during the interviews. Questions were developed through a collaboration with research colleagues who have experience with the research study's demographic. By cross referencing questions with field experts, researchers were able to gain face validity. Once data was collected and interviews were transcribed, themes were discovered among participants' responses.

Procedures

To begin collecting data, participants had to answer “yes” to the following questions: In your role as a social work practitioner, do you have experience working with caregivers who identify as the offspring of their care recipient? Are you willing to voluntarily take part in the study? After both questions were answered “yes”, an interview was conducted at a date and time most convenient to the participant. Interviews were made available to those willing to extend their time and share their experience. Each participant was provided via email with a consent form to complete and return prior to interview. Participants were not monetarily compensated but their time and contributions to this study were verbally acknowledged. Data collection was completed during the Fall Semester of the 2020-2021 school year.

Protection of Human Subjects

The identity of the individuals who participated in this research study were kept completely confidential. All participants received an informed consent form which they read and signed prior to taking part in this research study. In addition, they consented to be audio recorded during interviews. All data obtained including audio recordings were stored with password encryption in a USB drive and kept locked in the researcher’s safe located in the research advisor’s office located within the Social and Behavioral Sciences building at CSUSB. In order to avoid the risk of having information that could identify any participant, interviewed

participants were given pseudonyms and all pseudonyms were assigned a number for transcription.

Data Analysis

Through the use of qualitative design consisting of interviews, audio recordings were obtained and transcribed. Once transcribed, researchers analyzed the transcribed data in order to identify themes through the use of thematic analysis. Interview questionnaire can be found in Appendix B.

Summary

This research study analyzed the lived experiences of individuals who have cared for a sick or elderly parent and explored ways in which these experiences can be improved. The findings of this study can assist social work practitioners and other providers in improving their ability to better meet the needs of both caregivers and care recipients. The use of qualitative research in this research study provided researchers with the opportunity to acquire the information necessary to achieve the desired outcome of this study.

CHAPTER FOUR

RESULTS

Introduction

This chapter presents the findings of the eight interviews conducted with eight professional social work practitioners from different areas within the field of social work. Researchers administered interviews to gain a better understanding of social work practitioners' perspectives on the effects of caregiving on caregivers who are offspring to their care recipient. The following tables will present people, places, things, feelings/emotions, and ideas found within the interview transcripts. Data obtained from interviews were analyzed in order to find the common themes within participants' responses. A brief description of demographics has been presented as well.

Analyses

Table 1 provides demographic information for each of the participants. The sample consisted of eight female professionals in the field of social work, with all participants holding an Master of Social Work (MSW) or Licensed Clinical Social Worker (LCSW) credential. Of the eight respondents, four self-identified as Hispanic, two self-identified as Caucasian, and two self-identified as African American. The ages of the participants ranged from 28 to 46 years old, with a mean age of 35.75. Job titles and years of experience in the field of social work

have been included as well. To be considered for this study, participants were required to have experience working with this study's population of interest.

Tables 2-6 provide information gathered through thematic analysis which yielded common themes and trends among participants' responses. This method was utilized in order to identify similarities among the experiences of caregivers who are offspring to their care recipients; as described through the lens of social work practitioners who have worked with these caregivers. People, places, things, emotions/feelings, and ideas were collected from participants' responses and organized into tables which allowed for a clear understanding of the themes that resulted from these interviews.

Data Thematic Results

The research question being addressed in this study was: How does role reversal between parent and offspring affect the offspring (now caregiver)? As an exploratory study, this question was designed to illustrate the experiences of caregivers as told through the perspective of social work practitioners who have worked alongside these caregivers and their care recipients. From the data collected a series of themes among participants' responses were discovered: caregiving impacts relationships among family members, priorities among caregivers change and/or sacrifices are made, lack of access to resources leads to burnout, caregiving can often result in experiencing negative

emotions/feelings, and lack of support from family members intensifies the struggles that caregivers experience.

Table 1. Demographics of Research Participants

Demographic	Participant Response
Age	28, 30, 30, 35, 36, 39, 42, 46
Education Level	MSW, MSW, MSW, LCSW, MSW, MSW, MSW, LCSW
Job Title	Medical Social Worker, Hospice Social Worker, Ambulatory Care Social Worker, Bilingual Family Consultant, Bilingual Family Consultant, Medical Social Worker, Nephrology Social Worker, Social Services Director
Years in the Field	4, 2, 3, 10, 8, 9, 12, 15

Table 2. Research Category: People

Content/Theme
<ul style="list-style-type: none"> • Caregiver/ Private caregiver/ Older/ Younger caregiver • Parent/ Mom/ Dad • Children/ Child/ Kids • Patients/ Patients with dementia

- Social Worker/ Medical Social Worker
- Offspring/ Women offspring
- Family member/ Loved ones
- Sitter

Table 3. Research Category: Places

Content/Theme
<ul style="list-style-type: none"> • Home/ House/ Nursing home • School • Work place • Clinic/ Hospital • Inland Caregiver Resource Center/ Agency

Table 4. Research Category: Artifacts- Abstract

Content/Theme
<ul style="list-style-type: none"> • Role Reversal

- Programs/ IHSS/ Respite/ Referrals/ Resources
- Burnout
- Relationships
- Support/ Family support/ Help
- Medi- Cal/ Medicare
- Power of attorney/ Decisions/ Responsibilities
- Workshop
- Hospice/ Home Health/ Treatment
- Health
- Money
- Sacrifice
- Dynamic
- Barrier/ Barriers
- Self-care
- Sandwich generation
- Conflict
- Outlet
- Resilience
- Break

Table 5. Research Category: Feelings/ Emotions

Content/Theme
<ul style="list-style-type: none">• Guilt/ guilty• Emotional• Judging• Validated• Overwhelmed• Patience• Exhausted• Frustrated• Angry• Emotional

Table 6. Research Category: Ideas

Content/Theme
<p>(Personal Communication, Participant 1, October 2020):</p> <ul style="list-style-type: none">• “...they're focused on two things, work and then they get home and they have to still be a caregiver so it's almost like they don't get a break.”

- “...either other siblings aren't helping or they just don't have anyone else to help, so they're at home all the time.”
- “I think feeling overwhelmed and not feeling like they have enough time to even go to these resources or, you know, attending things.”
- “I would say that I see a lot of role reversal.”
- “So, with patients like with dementia, there's a lot of like redirecting them almost treating them like they're the child.”

(Personal Communication, Participant 2, October 2020):

- “...if they're young, a lot of the times they are sacrificing time with their family, you know, school, maybe they've stopped going to school for a little bit.”
- “Another thing that I've observed is me having to remind caregivers that it's ok to take breaks when I could tell they are burnt out.”
- “There's a lot of lack of family support.”
- “I don't think that people realize how much caregiving takes until you actually do it.”
- “...it kind of like it flips around like you're my mom and I'm your daughter but now I'm your mom and you are my daughter”

(Personal Communication, Participant 3, April October 2020):

- “I say it is a dramatic life change for them.”

- “Majority of the referrals that I receive at work are for assistance with caregiving.”
- “And pretty much a lot of our Baby Boom population, don't have the income to pay for a private caregiver which ranges from \$15 to \$32 per hour.”
- “...their stubbornness or they don't want to listen, they are frequently arguing or frequently fighting, and then the social worker becomes the referee.”

(Personal Communication, Participant 4, October 2020):

- “So a lot of times the only break that they get away from the patient would be when the patient is here for treatment.”
- “Not until resources are presented to them do they ever have some assistance, or do they feel like there is relief.”
- “...they don't have other people that can step in and help them, or our patient doesn't want anybody else but them to be the ones to assist.”
- “I think it makes the parent-child relationship more difficult on the child doing the caregiving just because they're put in a position where they have to tell their parent like you can have this you can't have that.”
- “I think the children tend to sometimes feel a little bit of resentment just because so much pressure has been put on them.”

(Personal Communication, Participant 5, October 2020):

- “I noticed that like most of them feel really isolated.”
- “...basically their whole life revolves around their parents.”
- “So constant guilt for like, ‘Oh, I need to go to the doctor, but how can I go to the doctor if my loved one is dying.’”
- “...most of them don't even use the resources available, because they don't have anyone to watch their parents when they leave.”
- “Lack of involvement from, like, the family itself and honestly lack of resources within the community. And there's nothing to give the caregiver a break, there's nothing really there.”
- “They have like a lack of authority with their parents, like they reverse their roles, but without the authority of it.”

(Personal Communication, Participant 6, October 2020):

- “I see a lot of caregivers putting themselves in the backburner, they prioritize their care recipient.”
- “They often have to put school on hold, or take a leave from work or, you know, they have to make a lot of sacrifices.”
- “They can't avoid the burnout because they're limited on resources, or they don't know that there's resources available to them.”

- “Or sometimes there's that conflict of the parent, being the care recipient, and still wanting to do the parent role, so that kind of strains the relationship.”
- “It's really rare when I see offspring come together and take care of their parents, it usually always falls on one person.”

(Personal Communication, Participant 7, October 2020):

- “Their priorities have changed, they are 100% committed to caregiving, and the priority becomes to the loved one which means that they no longer have time for themselves or self-care.”
- “And then they start feeling angry and resentful like they've been cheated in life.”
- “A lot of caregivers feel guilt if they want to do something for themselves.”
- “...especially the younger caregivers, their whole lives get put on hold, whether it be school, work, family, their relationships are strained with spouses or their significant other.”

(Personal Communication, Participant 8, October 2020):

- “I have seen caregiving affect caregivers differently depending on their stage of life.”

- “I’ve had clients admit to not pursuing certain goals that entailed distance from their parent such as traveling or moving out of state for school. It crushes their dreams.”
- “And in middle aged women I see them try to juggle taking care of their elderly parent while taking care of their young children as well, what they call the ‘sandwich generation.’”
- “I see that they have to juggle with their own illnesses while still being the caregiver.”
- “And one of the main reasons why our clients can't attend the workshops is because they don't have someone to take care of their care recipient, their loved one, not even for a couple of hours.”
- “I've had clients where respite hours are available for their care recipient, but the care recipient doesn't want to be looked after by a stranger.”
- “So I guess I would say that just the lack of immediate support from family or friends that can step in for a couple of hours.”
- “...and this person usually feels the obligation to step up because no one else is stepping up.”

Summary

By utilizing a qualitative approach to gather data through one-on-one interviews with social work practitioners, this study aims to illustrate the experiences of caregivers who are offspring to their care recipient. Through the use of thematic analysis, findings were categorized into people, places, things, feelings/emotions, and ideas. After being classified into tables, responses were analyzed and themes emerged. The following chapter will provide a more thorough explanation of these themes.

CHAPTER FIVE

DISCUSSION

Introduction

This chapter contains a discussion of the core findings that developed from this study: caregiving impacts relationships among family members, priorities among caregivers change and/or sacrifices are made, lack of access to resources leads to burnout, caregiving can often result in experiencing negative emotions/feelings, and lack of support from family members intensifies the struggles that caregivers experience. In addition, recommendations for social work practice, policy, and research are made, followed by a conclusion based on the core findings from this study.

Discussion

After a review of the data, responses provided by participants generated several themes that appeared to be common among caregivers' experiences. The first dominant theme was that caregiving impacts relationships among family members. It was implied by all participants that caregiving for a parent causes a role reversal between parent and offspring, as characterized by a switch in roles as offspring becomes the caregiver and parent becomes the care recipient. Participant 3 provided insight into this, "...it kind of like it flips around like you're my mom and I'm your daughter but now I'm your mom and you are my daughter" (Survey interview, October 2020). However, this role reversal does not always

allow the parent to preserve their authoritative role and on the other hand, it does not automatically provide the offspring with the authority that their new role implies. As it was suggested by participant 5, “They have like a lack of authority with their parents, like they reverse their roles, but without the authority of it.” (Survey interview, October 2020). As preexisting roles clash with those created as role reversal occurs, it can lead to conflict between parent and offspring which will ultimately strain the relationship. In her role as a social worker, one of the participants shared that she has had to act as a “referee” between a parent and their offspring due to the constant arguing and fighting between them. In another example shared by participant 4, she stated “I think it makes the parent-child relationship more difficult on the child doing the caregiving just because they're put in a position where they have to tell their parent like you can't have this you can't have that” (Survey interview, October 2020). This exchange of roles can often come at the expense of the caregiver and eventually lead to burnout.

A second theme found in the data was that priorities suddenly change for caregivers, often resulting in having to make sacrifices in their daily lives. As participant 7 stated, “Their priorities have changed, they are 100% committed to caregiving, and the priority becomes to the loved one which means that they no longer have time for themselves or self-care.” (Survey interview, October 2020). For most caregivers, their new role as care providers to their parents becomes another important and difficult aspect of their lives. As the data suggests, they no longer prioritize themselves and often make sacrifices in regards to their personal

goals in life. For example, as it was illustrated by participant 7, "...especially the younger caregivers, their whole lives get put on hold, whether it be school, work, or starting a family of their own" (Survey interview, October 2020). Other caregivers who have a family of their own can find themselves providing care for their parents and their own children at the same time. As participant 8 reported, "in middle aged women I see them try to juggle taking care of their elderly parents while taking care of their young children as well, what they call the 'sandwich generation'" (Survey interview, 2020). This leaves caregivers having to balance caring for their parents while also having to care for their children; a balance which is difficult to achieve due to the amount of work that both require.

Oftentimes, in an attempt to try and facilitate caring for both, parents may need to move in with their offspring and this means a disruption to the family structure within the home. Moving a parent into their home may mean moving a child out of their own bedroom, or taking up space that was not available to begin with. If the parent requires the use of durable medical equipment in order to assist them in their activities of daily living, it might result in the need to make adjustments to the home such as a ramp for a wheelchair, or handlebars in the restroom. In addition, having to care for children and an ill or elderly parent under the same roof may require preparing different meals for special diets, result in additional house chores, restrict ability for family outings, and overall can create more stress.

A third theme found in the data was that a lack of access to resources leads to burnout among caregivers. As participant 6 stated, “caregivers can't avoid the burnout because they're limited on resources, or they don't know that there's resources available to them.” (Survey interview, October 2020). Many caregivers do not know about the available resources to them or about non-profit organizations such as the Inland Caregiver Resource Center who focus on caregivers' needs. Other factors that can lead to burnout as shared by participant 5 are “Lack of involvement from, like, the family itself and honestly lack of resources within the community. And there's nothing to give the caregiver a break, there's nothing really there.” (Survey interview, October 2020).

Inland Caregiver Resource Center is an agency that provides services such as family consultation, caregiver support groups, short term counseling, and respite hours. The services offered by this organization are meant to help avoid caregiver burnout. However, if the caregiver lacks the time to attend support groups, or the respite hours offered are not used due to care recipient expressing resistance to being cared for by a stranger, then despite the help that is available burnout may still become inevitable. As illustrated by participant 8, “one of the main reasons why our clients can't attend the workshops is because they don't have someone to take care of their care recipient, their loved one, not even for a couple of hours.” (Survey interview, October 2020). Services such as In-Home Support Services (IHSS), provide an alternative since caregivers who qualify for this program are financially compensated for the care they provide to their

parents. However, this program is only eligible for Medi-Cal recipients which restricts access to many caregivers since qualifying for Medi-Cal can be challenging due to its requirements.

Another common theme found in the data was that caregiving can often result in caregivers often experiencing negative emotions/feelings. The stresses of life which most experience can be intensified when an individual takes on the role of caregiver. As participant 4 stated, "I think the children tend to sometimes feel a little bit of resentment just because so much pressure has been put on them." (Survey interview, October 2020). It appears that some of the pressure comes from the relationship between parent and offspring, which impacts the quality of care that the caregiver provides since in most cases there is an existing emotional connection between parent and offspring. In addition, as participants' responses suggest, caregivers become so consumed with their role that they feel guilty for doing things for themselves such as taking care of their own health. As illustrated by participant 5, "So constant guilt for like, 'Oh, I need to go to the doctor, but how can I go to the doctor if my loved one is dying.'" (Survey interview, October 2020). Hesitation to step away from their caregiving duties for important things such as their own health routine check-ups can result from the development of the fear that something bad can happen to their parent while they are away, even if it is just for a couple of hours. As well as acknowledging that if something were to happen they would blame themselves for being away. That is why caregivers have a decline in their health, high levels of physical strain, suffer

higher levels of stress, depression, anxiety, and other mental health effects. Along with their physical and mental health, participant 7 shared how these caregivers present with negative emotions and feelings as well, “they start feeling angry and resentful like they've been cheated in life.” (Survey interview, October 2020). Reported feelings of anger, frustration, helplessness, or guilt as a result of providing care can lead to constant worry, a decrease in self- esteem, loss of self- identity or uncertainty and less control of their lives as illustrated by participants’ responses.

The final theme found in the data was that lack of support from family members intensifies the struggles that caregivers experience. Participant 5 stated, “...most of them don't even use the resources available, because they don't have anyone to watch their parents when they leave” (Survey interview, October 2020). Even if the parent care recipient has multiple children, as shared by participant 6, “It's really rare when I see offspring come together and take care of their parents together, it usually always falls on one person” (Survey interview, October 2020). Feelings of isolation can arise due to lacking the support from other family members to assist in caring for a parent, resulting in caregivers not having any time to spend with peers or partake in activities outside of the home. The lack of family support can also cause resentment from the caregiver towards his or her siblings for being obligated to step up when no one else is stepping up.

Limitations

Despite the contributions that this study provides to the field of social work, its limitations must also be considered. This study was conducted during the COVID-19 pandemic and as a result, its methods for data collection had to be modified. Due to the many safety protocols that were put into place during the pandemic, direct access to this study's population of interest was lost and research in the form of interviews was conducted among a sample of eight social work practitioners who had worked directly with this population. This presents a limitation because it meant that the experiences of caregivers were presented through the views and interpretations of social work practitioners, which could have potentially yielded different results than those obtained from direct interviews with caregivers.

Another limitation is the disproportionate ratio of the gender of the participants who were interviewed for this study. Of the eight social work practitioners who participated, all identified as female which means there was no male representation. A sample that lacks multidimensional perspectives can result in findings that cannot be applied to the general population. In addition, another limitation related to the participants of this study is the potential for biased perspectives due to the possibility of burnout among the social workers who were interviewed. Those experiencing burnout may project negative views about their work with caregivers, resulting in biased data that is not representative of the experiences of this study's population of interest.

Recommendations for Social Work Practice, Policy, and Research

As this and future research studies continue to shed light into the effects of the role reversal that occurs when offspring become caregivers to their ill or elderly parents, may this research study provide social work practitioners with useful insight into the experiences of these individuals in order to better serve them. Enhancing social work practitioners' understanding of the experiences of caregivers could indicate that they will be able to provide more adequate support services to this growing population. Therefore, it is recommended that MSW programs implement courses that further educate social work students on the importance of understanding the needs of both, care recipients and caregivers.

In addition, as indicated by the findings of this research study, a lack of access to resources can oftentimes lead to burnout among caregivers. This suggests that services such as In-Home Support Services (IHSS) and other government funded programs must be extended in order to provide access to more individuals. Furthermore, investing in organizations such as the Inland Caregiver Resource Center whose efforts are dedicated to helping families as they face the challenges associated with caregiving will help expand access to those in need. It is recommended that future policy guided by the findings of this and similar studies focuses on ensuring that caregivers are provided with the support services they need in an effort to prevent adverse experiences, such as those illustrated by the participants in this study.

As previously mentioned, this study was conducted during the COVID-19 pandemic which affected researchers' access to caregivers resulting in the modification of the data collection procedures. Instead, social work practitioners with professional experience working with caregivers were recruited and interviewed virtually via Zoom. It is recommended that as pandemic restrictions are lifted and it is once again safe to interact face to face with individuals, future research involves interviewing caregivers directly. In doing so researchers might be able to improve the quality of data collected as suggested by the fact that when told by another person, the experiences of caregivers might be misconstrued. Another consideration for future research must be the inclusion of a more diverse group of participants, one which consists of different genders, cultural backgrounds, ages, and other identifying characteristics that result in a group that is more representative of the general population. Lastly, it is recommended that future research expands on existing data regarding the financial impact of caregiving in order to enhance efforts to enact policies that can broaden access to resources.

Conclusion

This study was developed with the purpose of gaining a better understanding of the effects of the role reversal that occurs between a parent and their adult offspring, as the parent becomes elderly or ill and requires the offspring to provide care. Overall, the findings of this study support the need for future research to continue to highlight and bring awareness to the experiences

of caregivers. By doing so, social work practitioners and other professionals who interact with care recipients and their caregivers can provide services that better address the specific needs of this population.

APPENDIX A
INFORMED CONSENT

INFORMED CONSENT

The study in which you are asked to participate is designed to examine the effects that caregiving has on caregivers. The study is being conducted by Antonio Quezada and Daisy Zamorano, graduate students, under the supervision of Dr. Thomas Davis, Assistant Professor in the School of Social Work at California State University, San Bernardino (CSUSB). The study has been approved by the Institutional Review Board at CSUSB.

PURPOSE: The purpose of this research study is to better understand the experiences of individuals who have undertaken the huge task of caring for a parent. Research focuses on the effects that caregiving has on caregivers, with an emphasis on how their role as caregivers impacts their mental, emotional, and physical health.

DESCRIPTION: Participants will be asked a number of questions on their experience and observations with working with caregivers in order to gain some insight on the effects of role-reversal between caregiver (offspring) and care recipient (parent).

PARTICIPATION: Your participation in the study is totally voluntary. You can refuse to participate in the study or discontinue your participation at any time without any consequences.

CONFIDENTIALITY: Your responses will remain confidential and data will be reported in group form only.

DURATION: It will take 30 to 60 minutes to complete the interview.

RISKS: Due to the fact that caregiving for a parent might be perceived as a sensitive subject, this research study poses minimal risk to interviewees. This minimal risk is based on the possibility that interviewees might have had experienced caring for a parent themselves, leading to an emotional reaction to the questions provided during the interview. Interviewees may terminate interview at any point.

BENEFITS: There will not be any direct benefits to the participants. However, findings from the study will contribute to our knowledge in this area of research.

CONTACT: If you have any questions about this study, please feel free to contact Dr. Davis at (909) 537- 3839.

RESULTS: Results of the study can be obtained from the Pfau Library ScholarWorks database (<http://scholarworks.lib.csusb.edu/>) at California State University, San Bernardino after July 2021.

.....
I agree to have this interview be audio recorded: ____ YES ____ NO

I understand that I must be 18 years of age or older to participate in your study, have read and understand the consent document and agree to participate in your study.

Place an X mark here

Date

APPENDIX B
INTERVIEW QUESTIONS

Research Study Questionnaire

Demographics

Job Title:

Age:

Gender:

Education level:

Number of years working in the field:

Interview Questions

1. From your observations working with caregivers, how has caregiving affected their life? (work, school, leisure time, mental, emotional and physical...etc.)
2. From your observations working with caregivers, do you find that they have knowledge of the resources available to help avoid caregiver burnout?
3. From your experience working with caregivers, what were the most common barriers that caregivers faced in avoiding caregiver burnout?
4. From your experience working with caregivers, have you observed the ways in which becoming a caregiver for a parent has affected their relationship with their parent?
5. From your experience working with caregivers, have you encountered situations in which the caregiver (offspring) has had to make life changing decisions on behalf of their parent (care recipient)?
6. From your experience working with caregivers, have those caregivers you have worked with had the choice of not becoming the primary caregiver to their parent?

Developed by Antonio Quezada and Daisy Zamorano

APPENDIX C
INSTITUTIONAL REVIEW BOARD APPROVAL EMAIL



CSUSB INSTITUTIONAL REVIEW BOARD
Administrative/Exempt Review Determination
Status: Determined Exempt
IRB-FY2020-246

Antonio Quezada Thomas Davis, Daisy Zamorano
CSBS - Social Work
California State University, San Bernardino
5500 University Parkway
San Bernardino, California 92407

Dear Antonio Quezada Thomas Davis, Daisy Zamorano

Your application to use human subjects, titled "Effects of Role Reversal Between Parent and Adult Offspring" has been reviewed and approved by the Chair of the Institutional Review Board (IRB) of CSU, San Bernardino has determined your application meets the federal requirements for exempt status under 45 CFR 46.104. The CSUSB IRB has not evaluated your proposal for scientific merit, except to weigh the risk and benefits of the study to ensure the protection of human participants. The exempt determination does not replace any departmental or additional approvals which may be required.

You are required to notify the IRB of the following as mandated by the Office of Human Research Protections (OHRP) federal regulations 45 CFR 46 and CSUSB IRB policy. The forms (modification, renewal, unanticipated/adverse event, study closure) are located in the Cayuse IRB System with instructions provided on the IRB Applications, Forms, and Submission webpage. Failure to notify the IRB of the following requirements may result in disciplinary action.

- Ensure your CITI Human Subjects Training is kept up-to-date and current throughout the study.
- Submit a protocol modification (change) if any changes (no matter how minor) are proposed in your study for review and approval by the IRB before being implemented in your study.
- Notify the IRB within 5 days of any unanticipated or adverse events are experienced by subjects during your research.
- Submit a study closure through the Cayuse IRB submission system once your study has ended.

If you have any questions regarding the IRB decision, please contact Michael Gillespie, the Research Compliance Officer. Mr. Michael Gillespie can be reached by phone at (909) 537-7588, by fax at (909) 537-7028, or by email at mgillesp@csusb.edu. Please include your application approval number IRB-FY2020-246 in all correspondence. Any complaints you receive from participants and/or others related to your research may be directed to Mr. Gillespie.

Best of luck with your research.

Sincerely,

Donna Garcia

Donna Garcia, Ph.D., IRB Chair
CSUSB Institutional Review Board

DG/MG

REFERENCES

- Abraham, K. M., Stein, C. H. (2012). Emerging adults' perspectives on their relationships with mothers with mental illness: Implications for caregiving. *American Journal of Orthopsychiatry, 82*, 542-549
- American Psychological Association. (2015). *Mental and Physical Health Effects of Family Caregiving*. Retrieved from <https://www.apa.org/pi/about/publications/caregivers/faq/health-effects>
- American Psychological Association. (2011). *What Do Family Caregivers Do?*. Retrieved from <https://www.apa.org/pi/about/publications/caregivers/faq/family>
- Caton, C. L. M., F., Felix, A., & Wyatt, R. J. (1998). Childhood experiences and current adjustment of offspring of indigent patients with schizophrenia. *Psychiatric Services, 49*, 86-90.
- Center on Aging Society. (2005). *How Do Family Caregivers Fare? A Closer Look at Their Experiences*. (Data Profile, Number 3). Washington, DC: Georgetown University.

Commonwealth Fund. (2005). Issue Brief: A Look at Working- Age Caregivers'

Roles, Health Concerns, and Need for Support. Retrieved from

<http://commonwealthfund.org>

Family Caregiver Alliance. (2006). *Caregiver Health*. Retrieved from

<https://www.caregiver.org/caregiver-health>

Easters Seal & National Alliance for Caregiving. (2007). *Caregiving in Rural*

America. Retrieved from

<http://www.easterseals.com>(<http://www.easterseals.com>)

Family Caregiver Alliance. (2016). *Caregiver Statistics: Demographics*. Retrieved

from <https://www.caregiver.org/caregiver-statistics-demographics>

Gérain, P., & Zech, E. (2019). Informal Caregiver Burnout? Development of a

Theoretical Framework to Understand the Impact of Caregiving. *Frontiers*

in Psychology, 10(JULY), 1748.

Grunfeld, E. (2004). Family caregiver burden: Results from a longitudinal study of

breast cancer patients and principal caregivers. *Canadian Medical*

Association Journal, 170(12): 1795-1801

Jurkovic, G. J. (1997). *Lost childhoods: The plight of parentified child*. New York,

NY: Brunner/ Mazel Inc.

- Life Expectancy At Birth, Total (years) - United States. Retrieved from
<https://data.worldbank.org/indicator/SP.DYN.LE00.IN?locations=US>
- Marks, N. Lambert, J. D., & Choi, H. (2002). Transitions to caregiving, gender, and psychological well-being: A prospective U.S. national study. *Journal of Marriage and Family*, 64, 657-667
- National Alliance for Caregiving and AARP. (2015). *Caregiving in the U.S.* Retrieved from https://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June
- Pinquart, M. & Sorensen, S. (2003) Differences between caregivers and noncaregivers in psychological health and physical health: A meta analysis. *Psychology and Aging*, 18(2), 250-267
- United States Centers for Medicare and Medicaid Services. (ND) PACE Programs of All-Inclusive Care for the Elderly. Retrieved from <https://www.medicare.gov/your-medicare-costs/get-help-paying-costs/place>
- Zarit, S. (2006). Assessment of Family Caregivers: *Voices and Views from the Field*. Report from a National Consensus Development Conference (Vol. II) (pp. 12 - 37). San Francisco: Family Caregiver Alliance.

ASSIGNED RESPONSIBILITIES PAGE

This research project has been a collaboration between Antonio Quezada and Daisy Zamorano. From the time the research question was developed, all responsibilities were divided equally. Research was conducted simultaneously by both parties, including the gathering of information to develop the literature review and the conceptualization of a study design most appropriate for the research question.