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Experiences of Rural Female Caregivers of Loved Ones Diagnosed With Chronic Pain and Mental Health Care

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Walden University
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Abstract

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by

Anne Banner Hatfield

MSSW, University of Texas at Arlington, 1993

BSW, Texas Christian University, 1989

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

The complex diagnosis of chronic pain can include both physiological and psychological symptoms resulting in a need for caregivers to assist their loved ones and become involved in their mental health care treatment. As the aging population and the number of individuals diagnosed with chronic pain increases, the number of caregivers who assist them also increases. Critical to addressing the psychological symptoms of chronic pain is knowing how caregivers experience their involvement in mental health treatment. This research addressed the need for an understanding of caregivers' experiences of caregiving and involvement with health care providers of mental health treatment for their loved ones. The purpose of this qualitative, hermeneutic phenomenological study was to explore the lived experiences of a purposive and snowball sample of 12 female caregivers living in the rural Southwestern region of the United States. Data were collected through semistructured interviews. Emergent themes regarding the discomfort with the label of caregiver and diagnosis of mental health symptoms were derived from a modified van Kaam method of data analysis. Additional core themes included the subthemes of the caregivers' experiences advocating for and supporting their loved ones' decision making and treatment options. All 12 caregivers reported that by spending time with their loved one, the loved ones' well-being increased and mental health symptoms decreased. The results of this study have potential implications for positive social change by extending health care professionals' knowledge about how caregivers experience mental health care treatment for their loved ones.

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Dedication

I dedicate this study to my mother, Judith Banner who has taught me through her example about gracious, generous, and loving caregiving.

Acknowledgments

To all of my family members, I thank you for your love, encouragement, and support over these many years.

To my chair, Dr. Debra Wilson, and committee members, Dr. Alice Yick and Dr. Savvas Georgiades, I thank you for your time and guidance in this process.

To the women who participated in the study, I thank you for your time and assistance in openly sharing your stories with me.

To my friends, I thank you for sharing my laughter and tears throughout this marathon.

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Chapter 1: Introduction to the Study

Introduction

In the United States, 19% to 43% of the population are diagnosed with chronic pain depending on the source and the definition of *chronic pain* (Heijde et al., 2018; Jafarzadeh & Felson, 2018; Pitcher et al., 2019; Turner et al., 2017). Health care providers who interact with these individuals include physicians, nurses, social workers, psychologists, dieticians, and physical therapists. These professionals use medical and nonmedical treatments for chronic pain specific to rheumatic, musculoskeletal disease (RMD) incorporating medication, physical therapy, meditation, counseling, and diet (Fiest et al., 2017; Lim et al., 2017). Some patients diagnosed with RMD have difficulty independently accomplishing activities of daily living (ADLs), such as bathing, cooking or medical treatment compliance, and receive assistance from a family member (Andrews et al., 2017; Otero et al., 2019; Salehi-tali et al., 2017).

Researchers have examined how patients and health care providers experience the involvement of caregivers in health care treatment in general and regarding mental health (Berry et al., 2017; Hansen & Bjerrum, 2016). Researchers have reported on the effectiveness of several treatments for patients diagnosed with dementia, cancer, and diabetes that include caregivers (Berry et al., 2017; Morelli et al., 2019; Todorova et al., 2016). However, minimal research exists that includes caregivers' perceptions of their involvement in the mental health care treatment of patients diagnosed with chronic pain (Corvin et al., 2017; Morelli et al., 2019; Nowakowski & Sumerau, 2017; Salehi-tali et al., 2017; Vaughan & Kluger, 2018). Such involvement might include the caregiver accessing treatment services for their loved one, communicating with health care providers, and receiving psychosocial support or educational services (Lawton et al., 1989; Todorova et al., 2016; Vaughan & Kluger, 2018). This chapter includes information about this problem and the research to answer the question regarding description of the shared lived experiences of caregivers of patients diagnosed with RMD.

Background

Chronic pain or RMD is a complex diagnosis that frequently includes both physiological and psychological symptoms (Duenas et al., 2016; Toye et al., 2018). As both physical and psychological symptoms can restrict a patient's ability to independently accomplish ADLs, caregivers might assist with scheduling health care appointments, medication compliance, and transportation (Andrews et al., 2017; Otero et al.,2019). In the United States, and specifically the Southwestern region, caregiving for family members is culturally expected to be the responsibility of female family members and financial support is provided from male family members (Brenna et al., 2014; DiNovi et al., 2015). Many researchers have included only women in their research samples when they examined effects of caregiving on health and well-being (Bom et al., 2019).

A lack of mental health professionals, specifically psychiatrists, exists in rural communities; as a result, general practice physicians often treat patients' psychological and physiological symptoms of chronic pain (American College of Rheumatology, 2015). Health care providers might offer treatments, such as opioids and surgery, for the chronic pain, and they might also offer counseling and support for the subsequent mental health symptoms of chronic pain (Englbrecht et al., 2017; Fiest et al., 2017; Li et al., 2019). Researchers have found that health care providers are motivated to include caregivers in the assessment and treatment of their patients' chronic pain (Hansen & Bjerrum, 2016).

Health care providers report an increase in medical compliance and positive outcomes for patients who have caregivers involved in their health care (Hansen & Bjerrum, 2016). However, minimal research has been conducted that includes how caregivers' perceive their involvement in the mental health care treatment of the patient, and no research has been conducted to examine caregivers living in rural communities in the Southwestern region of the United States (Corvin et al., 2017; Morelli et al., 2019; Nowakowski &Sumerau, 2017; Salehi-tali et al., 2017; Vaughan & Kluger, 2018). Social workers might need a clear understanding of rural, female caregivers' experiences of involvement in mental health treatment for their loved ones diagnosed with RMD to create policies and services to best meet their needs (Duenas et al., 2016). The goal of this research was to help to fill this gap in the research.

Problem Statement

Approximately 52.9 million adults in the United States in 2015 had a diagnosis of RMD (Heijde et al., 2018; Jafarzadeh & Felson, 2018; Morelli et al., 2019). Of those, over 13 million patients report that the diagnosis has resulted in a need for significant assistance from nonprofessional caregivers with ADLs (Heijde et al., 2018; Morelli et al., 2019). Based on U.S. Medical Expenditure Panel Survey data from 2013 (as cited in Murphy et al., 2018), the combined cost of direct medical expenditures attributed to a diagnosis of RMD and the indirect cost of loss of earnings ranges between $303.5 billion and $326.9 billion. The calculation of indirect costs can also include professional and nonprofessional home care and loss of earnings of caregivers of patients diagnosed with RMD (Jowsey et al., 2016; Kindt et al., 2015). Without the assistance of nonpaid, relative caregivers, the direct and indirect costs would increase because patients would require expensive placements in hospitals, nursing homes, and assisted living facilities (Baumbauer et al., 2016; Chari et al., 2015). Specifically, as the responsibilities of patients transfer to caregivers (including income, cooking, cleaning, bathing, and feeding), the caregivers are likely to experience decreased physical, psychological, and social health (Chari et al., 2015; Duenas et al., 2016; Mohammadi et al., 2017). Social workers need a strong knowledge base to advocate for supportive policies and programs for caregivers (Duenas et al., 2016)

In examining the caregiver–patient dyad, previous researchers have focused on marital satisfaction, coping mechanisms, and quality of life among caregivers of patients diagnosed with chronic pain (Beggs et al., 2015; Junghaenel et al., 2017; Ruben et al., 2018; Uysal et al., 2017). Also, researchers have gathered data from health care providers' perspectives and patients' perspectives of including caregivers in the treatment and found positive outcomes for the patient (Helgeson et al., 2018). However, little research is available that includes the experiences of rural female caregivers of patients diagnosed with chronic pain when involved in mental health treatment for their loved ones (Duenas et al., 2016). Moreover, there appears to be a lack of empirical data about rural female caregivers of patients diagnosed with RMD including perceptions of involvement in mental health treatment in medical settings, specifically accessing treatment, communicating with the providers, and receiving support services (Milano, 2017; Morelli et al., 2019; Robinson-Lane & Vallerand, 2017). Researchers have reported that caregivers of family members are more likely to be female than male (Brenna et al., 2014; DiNovi et al., 2015).

Caregivers and loved ones living in rural areas of the Southwestern region of the United States have access to limited health care resources and providers with expertise in RMD (American College of Rheumatology, 2015). As a result of the limited psychiatric resources in rural communities, many patients receive treatment for mental health diagnoses of depression and anxiety related to RMD from internal medicine and family practice physicians (American College of Rheumatology, 2015). Social workers and other mental health care providers need information about these caregivers' experiences of involvement and interaction with health care professionals in offering mental health treatments to increase advocacy resulting in positive outcomes of services and policy implementation (Cagle & Bunting, 2017; Crowe et al., 2017; Hadi et al, 2017). To address this gap, I conducted a hermeneutical phenomenological study to seek to understand how rural female caregivers experience involvement with mental health treatment services offered in medical settings to loved ones diagnosed with RMD. My findings may be helpful to social workers in advocating for these caregivers to continue to care for loved ones for a protracted amount of time and a reduction in cost to society (Chari et al., 2015; Shugrue et al., 2019).

Purpose of the Study

For this hermeneutical phenomenological study, I explored the shared lived experiences of female caregivers (between the ages of 65 and 70) of patients diagnosed with chronic pain from RMD. Specifically, I was examining caregivers’ involvement with mental health treatment professionals, which might include physicians, psychologists, and social workers working in medical settings to address the gap in the literature regarding these caregivers’ experiences. In response to the increasing number of patients diagnosed with RMD requiring assistance with ADLs, caregivers contribute to patients’ ability to avoid expensive paid assistance and to remain in a preferred housing environment (Milano, 2017; Morelli et al., 2019; Shugrue et al., 2019). Findings from this research may include information constructive to medical social workers in advocating for improvement of interactions with caregivers and may fill a gap in the literature (Reynaert et al., 2019). Policy makers might use these findings to address the need for a reduction of indirect, nonmedical expenses as the number of patients diagnosed with chronic pain increases along with their reliance on caregivers (Chari et al., 2015; Shugrue et al., 2019).

Research Question

The research question that guided this study was: What are the shared lived experiences of female caregivers (ages 65 to 70) of patients diagnosed with RMD living in the rural Southwestern region of the United States, specific to their involvement with health care providers of mental health treatment of their loved ones?

Theoretical Framework

The theoretical framework for this study included two elements: constructivist theory and hermeneutics relative to the relationship with phenomenological research. I applied the hermeneutical phenomenological research method using my ontological lens of constructivism, as the sole researcher, to examine the phenomenon of caregivers' lived experiences of involvement with mental health providers in medical settings.

Constructivist Theoretical Framework

Constructivist theorists build on ontological relativity, endorsing the thesis that statements of existence depend on perspective or worldview (Denzin & Lincoln, 1994; Edwards, 2019; Guba & Lincoln, 1990). Epistemologically, philosophers of constructivism respect the transactional nature of the differences in power linking the participant and the researcher (Fuller, 2000). Kuhn (1962) advanced the importance of constructing truths through consensus rather than an attempt to prove or disprove an objective hypothesis and of embracing the potential for multiple truths or realities. As sole researcher for this hermeneutical phenomenological research, I used this theory to describe and interpret the information gathered from the participants consistent with the constructivist paradigm relative to potential differences in interpretation dependent on the worldview of any given sole researcher (Denzin & Lincoln, 1994; Edwards, 2019; Guba & Lincoln, 1990).

Hermeneutical Phenomenological Framework

Hermeneutical theorists focus on consciousness, meaning, and essence to describe or interpret experiences of individuals (Edwards, 2019; Heidegger, 1927; Moustakas, 1994). I conducted a hermeneutical phenomenological research study involving the reflective–interpretative processes of examination of intention and meaning (Heidegger, 1927; Moustakas, 1994). Specifically, the relationship between my prejudgments of what the caregivers of patients diagnosed with RMD are experiencing in the medical settings and the view of the data gathered can create new prejudgments (Heidegger, 1927; Moustakas, 1994). I interpreted the thematic patterns in the descriptive texts from the caregivers relative to the conscious and underlying meanings offered that account for these experiences (Moustakas, 1994).

Nature of the Study

For this study, I used a hermeneutical phenomenological research method to explore the shared lived experiences of female caregivers of patients diagnosed with RMD specifically related to interactions or involvement with mental health care providers in a rural Southwestern region of the United States (Edwards, 2019; Moustakas, 1994). I examined participants' experiences of involvement through interactive interviews with 12 caregivers, to the point of theoretical saturation, of patients diagnosed with RMD. I collected data through semi structured interviews and used the data to create descriptive text for a modified van Kaam analysis (Moustakas, 1994).

Interpreting the data involves a process of recognizing meaning as expanding and expandable; therefore, I monitored my prejudgments while remaining consistent with the assumptions of hermeneutic phenomenological research (Edwards, 2019; Heidegger, 1927; Merleau-Ponty & Smith, 1966). I recruited caregivers as research participants identified through purposive and snowball sampling techniques. All research participants had to meet inclusion criteria as female caregivers (ages 65–70) of patients diagnosed with RMD living in the Southwestern region of the United States. These recruitment methods are consistent with hermeneutical phenomenological research methods and the research question (Moustakas, 1994). The use of semi structured interviewing allows for increased two-way communication between researcher and participants to emphasize the focus on deeper, broader data collection (Castillo-Montoya, 2016; Moustakas, 1994;).

Definitions

The following key terms and definitions provided overall clarity throughout the hermeneutical phenomenological research study.

Caregiver: A family member assisting a patient with ADLs (Andrews et al., 2017; Otero et al., 2019).

Chronic pain: Pain lasting longer than 3 months, resulting from a complex interaction between biological and psychosocial elements related to the immune system, deterioration of the joints, and inflammation (Baumbauer et al., 2017; Crowe et al., 2017; Duenas et al., 2016; Toye et al., 2018).

Health care providers: Individuals providing services as defined by the U.S. Department of Labor (2020), including but not limited to, physicians, nurses, psychologists, social workers, dieticians, and physical therapists.

Involvement with mental health providers: Interactions or communications, verbal or written, with health care providers assessing and/or treating the mental health diagnoses of patients diagnosed with chronic pain, including accessing services, education, and counseling (Reynaert et al., 2019; Todorova et al., 2016; Vaughan & Kluger, 2018).

Lived experience: The conscious description of how an individual finds the essence or meaning of a circumstance (Heidegger, 1927). This is specific to phenomenological study and requires a thorough and methodical examination of a human being's awareness through their senses (Moustakas,1994).

Medical settings: Inpatient and outpatient environments where health care services are offered, can include clinics or hospitals (Reynaert et al., 2019).

Rheumatic, musculoskeletal disease (RMD): Chronic pain and limited functioning that can be caused by over 200 different diagnoses, including rheumatoid arthritis as the most recognized and prevalent (Heijde et al., 2018). RMD has been described as a progressive disease characterized by pain and associated emotional, social, financial, and societal burden, which can cause decreased quality of life and life expectancy (Flurey et al., 2017; Heijde et al., 2018).

Assumptions

Hermeneutical phenomenologists presume that researchers cannot be thoroughly objective and subsequently attempt to clarify their prejudgments about the phenomenon (Heidegger, 1927; Moustakas, 1994). As the researcher in this study, I assumed the research participants would be communicative and forthcoming in understanding and answering the interview questions. I assumed participating caregivers would possess some level of awareness of their loved ones' chronic pain diagnosis and whether their loved one also exhibits symptoms of mental health diagnoses related to chronic pain, specifically depression or anxiety. I also assumed that participating caregivers would possess some level of interest in participating in this qualitative research.

Scope and Delimitations

This research was conducted to examine rural, female caregivers of loved ones diagnosed with chronic pain living in the Southwestern region of the United States. Women in the Southwestern region of the United States report a cultural expectation to be caregivers for loved ones experiencing a decreased ability to independently accomplish ADLs (Brenna et al., 2014). Researchers have studied data collected from patients and health care providers regarding the positive health outcomes for a patient when a caregiver is involved in their health care treatment (Berry et al., 2017; Hansen & Bjerrum, 2016). Researchers have also examined caregivers of patients diagnosed with chronic pain in studies related to quality of life, coping mechanisms, and marital satisfaction (Beggs et al., 2015; Junghaenel et al., 2017; Ruben et al., 2018; Uysal et al., 2017). However, little research has been conducted that includes caregivers' perceptions of involvement in mental health treatment for their loved ones (Duenas et al., 2016). In addition, a paucity of specialists with expertise in the complex physiological and psychological symptoms of RMD has been reported in rural communities (American College of Rheumatology, 2015). National Alliance for Caregiving and AARP Public Policy Institute (2015) reported a cultural expectation for women to be caregivers for their family members. Knowledge regarding the experiences of female caregivers living in rural communities might assist social workers in developing programs to support these caregivers in their responsibilities. Though other theoretical frameworks have been used to examine caregivers, including coping and family systems theories, this phenomenological study might capture thick, rich data illuminating the complexities of caregivers' shared lived experiences (Moustakas, 1994).

Limitations

The evidence provided in this hermeneutical phenomenological research design might not support transferability or the applicability of the findings to other contexts (Moustakas, 1994). I collected data by interviewing women who are caregivers for loved ones diagnosed with chronic pain; the findings may not be directly applicable to men, other caretakers, or other women. I interviewed women who live in the rural Southwestern region of the United States, which might hinder transferability to urban caregivers or those living in other regions of the United States. This process is reliant on the participant sharing information to form a text that can include challenges of unknown biases, problems of recall, and misunderstanding regarding the asked question (Moustakas, 1994). I recruited participating caregivers to the point of theoretical saturation, which might have excluded additional participants whose shared lived experiences had not been captured in the data. Differences in culture, context, and other variables of the participants might not be accurately considered, resulting in an exaggeration or denial of information regarding the lived experiences of caregivers (Pryma, 2017).

Significance

Of the 52.9 million adults in the United States diagnosed with RMD in 2015, approximately 13 million reported the need for assistance from a caregiver (Heijde et al., 2018). As the responsibilities of ADLs transfer from patient to caregiver, caregivers might experience involvement in their loved one’s mental health treatment in a medical setting (Baumbauer et al., 2016). Research focused on examining caregivers’ meaning or essence in interacting with health care professionals may help fill the gap in the literature and provide new perspectives to stakeholders, social workers, supportive health care professionals, and policy leaders (Reinhard & Young, 2019).

Due to the limited access to health care providers with expertise in RMD and resources for patients and caregivers living in rural areas, the results of this phenomenological study might support positive social change and the professional practices of rural social workers in medical settings in advocating for increased positive outcomes in offering emotional and instrumental support to caregivers (American College of Rheumatology, 2015; Milano, 2017; Reinhard & Young, 2019). Specifically, the findings might support social workers in community-based chronic disease self-management programs and encourage the inclusion of the caregiver–patient dyad in outreach, services, and support (Corvin et al., 2017). With an increased understanding of this phenomenon and the diverse experiences of caregivers, social workers and stakeholders involved in policy development and implementation might use the results to address the need for technology-based support and design other methods of approaching increasingly effective caregiver support services, which could also result in positive social change (Chari et al., 2015; Todorova et al., 2016; Vaughan & Kluger, 2018).

Summary

Caregivers of loved ones diagnosed with RMD might assist with ADLs, including involvement with providers of health care treatment for their loved ones' mental health diagnoses (Berry et al., 2017). Specifically, caregivers living in rural areas of the Southwestern region of the United States might have limited access to health care providers with expertise in RMD (American College of Rheumatology, 2015). Social workers and other mental health providers need information about caregivers' perceptions of involvement in their loved ones' mental health treatment to increase advocacy, which could result in positive social change outcomes through services and policy implementation (Cagle & Bunting, 2017; Crowe et al., 2017; Hadi et al., 2017). Chapter 1 included information regarding the problem statement, purpose, nature and significance of the research, the research question, theoretical framework, and limitations of the proposed research. In Chapter 2, I will cover a background of the key concepts, the search strategy used for the literature review, and a comprehensive review of the literature related to caregiving, chronic pain, RMD, treatment options, and the inclusion of caregivers in treatment.

Chapter 2: Literature Review

Introduction

The purpose of this hermeneutical phenomenological study was to advance the understanding of how female caregivers of loved ones who have been diagnosed with RMD living in rural areas of the Southwestern region of the United States experience involvement in their loved ones' mental health treatment. This chapter includes information about the strategy used to search the relevant literature, a brief history of the conceptual framework, and a history of caregiving. The chapter also includes relevant information regarding assessment and treatment of chronic pain and the caregivers' involvement in that treatment with a focus on mental health treatment. In appraising multiple studies written about caregiving in general and the specific relationship between caregivers and loved ones diagnosed with chronic pain, literature regarding the caregivers' perceptions of involvement in the mental health treatment of their loved ones was relevant to this research (Boehmer et al., 2014; Reinhard & Young, 2019; Ruddere et al., 2014). A study of caregivers might provide insight into the lived experiences of caring and advocating for patients diagnosed with chronic pain and subsequent adaptation of costs related to direct and indirect care for patients (Boehmer et al., 2014; Reinhard & Young, 2019). Social workers might use the results of this study to directly assist caregivers and indirectly encourage positive outcomes for their loved ones (Reinhard & Younger, 2019).

Literature Search Strategy

I acquired the literature for this study using information from the following databases: EBSCOhost, CINAHL, ERIC, Google Scholar, Medline, ProQuest, SAGE, and SocINDEX. I used the following search terms: *chronic pain, medical treatment for chronic pain, nonmedical treatment for chronic pain, caregivers of family members diagnosed with RMD, carers, spouses of patients diagnosed with chronic pain, and communication or interactions of caregivers with mental health providers in a medical setting, mental health services in a medical setting* and related terms of *hermeneutical phenomenological, phenomenology, phenomena, phenomenon,* and *qualitative study.* In addition, I used information from federal and state governmental sources such as the U.S. Department of Health and Human Services, National Institutes of Health, Administration on Aging, and Social Security Administration. My inclusion criteria were that peer-reviewed articles had to be published within the last 6 years or be substantiated as seminal works. Articles regarding caregivers of patients diagnosed with cancer or HIV were excluded (Baumbauer et al., 2015; Otero et al., 2019).

I located, read, and synthesized over 150 articles focused on positioning how caregivers experience involvement with the mental health treatment of loved ones who have been diagnosed with RMD. Although some information was redundant, I examined prior work to complete an exhaustive search. I also consulted texts from seminal theorists with phenomenological and caregiving expertise. I searched for older literature to determine the appropriateness of inclusion. Alternating between the terms *informal caregivers* and *relative caregivers*, I searched related disciplines to determine if similar results were available. An overview of integral literature is included in the subsequent paragraphs, specifically related to the proposed conceptual framework and then related to the key terms, including treatment of mental health symptoms of RMD, caregiving, and caregivers' involvement in their loved ones' mental health treatment.

Conceptual Framework

For this study's conceptual framework, I used a hermeneutic phenomenological research method to explore caregivers' shared lived experiences of involvement or interactions with their loved ones' health care providers. Researchers use qualitative research to gain an increased understanding of how individuals and groups describe experiences of the world (Denzin & Lincoln, 1994; Herber & Barroso, 2019; Moustakas, 1994). Qualitative researchers attempt to collect rich textured descriptions of significant depth and breadth using methodologies such as open-ended interviews and focus groups (Denzin & Lincoln, 1994; Moustakas, 1994). The following paragraphs contain a review of hermeneutical phenomenology, specifically the hermeneutic circle, intersubjectivity, and differences between two seminal theorists.

Phenomenological researchers focus on individual perceptions of societal problems and the meaning of those perceptions to the individual (Moustakas, 1994; Spence, 2017). Husserl originated the concept of a reflective approach to phenomenology (Edwards, 2019; Husserl, 1931; Stroh, 2015). Heidegger expanded the theoretical and descriptive approach of Husserl to an atheoretical approach, including description as well as interpretation (Edwards, 2019; Heidegger, 1927; Spence, 2017; Stroh, 2015).

Hermeneutical theorists focus on the concepts of meaning, being, and essence to describe and interpret experiences of individuals (Edwards, 2019; Moustakas, 1994). Hermeneutic phenomenologists examine how people make sense of their major life experiences and focus on understanding the lived experiences of participants through learning the meaning participants place on patterns and relationships (Dahlberg, 2006; Sloan & Bowe, 2013). Hermeneutic phenomenologists describe the lived experiences of others and how social, cultural, and political exposures influence worldviews (Moustakas, 1994; Spence, 2017; Stroh, 2015).

Hermeneutic Circle

The hermeneutic circle is a process used to interpret the text of experiences of individuals and groups through their shared stories (Giorgi, 2006; Stroh, 2015). Hermeneutic phenomenologists believe the meaning of the words people use regarding lived experiences inextricably exist as a way of being and that descriptions emerge from a reflexive interpretative process (Denzin & Lincoln, 1994; Edwards, 2019). Using hermeneutic phenomenology allows a researcher to describe the phenomenon of interest while admitting to and understanding personal presumptions and prejudices (Edwards, 2019; Stroh, 2015; Sturgess, 2016). Hermeneutic phenomenology theorists encourage the researchers to embrace the inability to separate language used in storytelling, which results from the dialogue between the researcher and the participant (Dahlberg, 2006; Spence, 2017). The hermeneutic circle is a process by which understanding can occur through the acknowledgment and adjustment or correction of prejudgments or preunderstandings as interpretative analysis of the text occurs (Stenner et al., 2017; Stroh, 2015). New and authentic understandings emerge from this circular process of continuous reexamination and adjustment of the proposed meaning found in the language of the text (Edwards, 2019; Stenner et al., 2017). I used the hermeneutic circle to understand the lived experiences of caregivers of loved ones diagnosed with RMD.

Intersubjectivity

In the hermeneutic circle, researchers explain how the meaning or perception of an experience of an individual informs the meaning or perception of the community, and the meanings of the community enlighten the meaning of the individual (Stroh, 2015; Sturgess, 2016). The individual or singular first-person perspective simultaneously exists in the context of the collective first person, and the converse is true (Gadamer, 1996; Stroh, 2015). The interaction back and forth between the two results in authentic interpretations of the phenomenon (Moustakas, 1994; Stroh, 2015). The hermeneutical philosophical stance is based on the belief that human beings are part of the world and are inseparable from the world (Heidegger, 1927; Sloan & Bowe, 2013). Heidegger (1927) described the relationship between self-understanding and world understanding as undividable.

Heidegger indicated that language is not simply words and concepts, but is the accumulation of units, activities, and relationships into a meaning that makes speech possible (Dahlberg, 2006; Spence, 2017). The main goal was to discover the essence of ordinary human existence through experiences (Heidegger, 1927; Moustakas, 1994). Hermeneutic phenomenologists place emphasis on exploring the stories people tell of their experiences and intently reflecting on what the transcripts reveal (Giorgi, 2006;

Heidegger, 1927; Sturgess, 2016). The research methodology includes locating participants who have met inclusionary criteria relative to the phenomenon, collecting data through techniques such as interviews and focus groups, and analyzing the resulting transcripts in an iterative process consistent with the hermeneutic circular process (Moustakas, 1994; Sloan & Bowe, 2013).

Difference Between Husserl and Heidegger

Husserl and Heidegger required researchers to have an open approach to the text, which allows unexpected understanding to emerge; however, a primary difference exists in the belief that a researcher can explicate the preconceptions from the research process (Edwards, 2019; Heidegger, 1927; Husserl, 1931; Moustakas, 1994). Husserl used the term *bracketing* to encourage researchers to set aside their thoughts, beliefs, and influences to describe a particular phenomenon (Husserl, 1931; Stroh, 2015). Heidegger encouraged researchers to accept the conscious and unconscious conceptions and thoughts as inevitable and inextricable (Denzin & Lincoln, 1994; Edwards, 2019; Heidegger, 1927). Heidegger explained that researchers could not disregard biases due to the intersubjectivity between the singular first-person perspective and the collective first-person perspective of human existence underlying and giving coherence to the ways of people (Heidegger, 1927; Sloan & Bowe, 2013; Spence, 2017; Stroh, 2015).

A hermeneutic researcher revises preconceptions allowing the development of new conceptualizations of meaning based on data collected (Moustakas, 1994; Stroh, 2015). When using the hermeneutic circle, I progressed in a cyclical direction of understanding of the phenomenon regarding the lived experiences of caregivers of loved ones who have been diagnosed with RMD. I choose Heideggerian hermeneutic phenomenology due to the support for active construction of an authentic understanding of the phenomenon.

Literature Review Related to Key Concepts

Phenomenologists disagree regarding the role of the literature review in the planning and undertaking of research (Denzin & Lincoln, 1994; Fry et al., 2017). Researchers might begin to conceptualize the research question, design, and methodology in an iterative process through discovering gaps in the current empirical evidence (Fry et al., 2017; Moustakas, 1994). A researcher might also be concerned about the prospective contamination of preconceptions while reviewing and reflecting on the information found in the literature (Fry et al., 2017). In planning the implementation of the research question, design, and methodology, I reviewed literature regarding the diagnosis and treatment of RMD, historical background of caregiving, and information about health care providers' and patients' perspectives of caregivers' involvement in health care treatment.

Rheumatoid Musculoskeletal Disease

This section includes information regarding the diagnosis and treatment of chronic pain, specifically RMD. Physicians report that pain functions as an evolutionary adaptive warning of damage to healthy, normal tissue and can assist in the promotion of healing of the tissue (Baumbauer et al., 2017; Crowe et al., 2017). The experience of chronic pain, defined as pain lasting longer than 3 months, is the result of a complex interaction between biological and psychosocial elements (Duenas et al., 2016; Toye et al., 2018). Acute pain is usually caused by trauma or injury whereas chronic pain can result from systemic problems related to the immune system, deterioration of the joints, and inflammation (Baumbauer et al., 2017; Crowe et al., 2017). Scientists state that risk factors for chronic pain can include changes to air or water quality through pollution, physically challenging strenuous occupations, obesity, or mood disorders (Baumbauer et al., 2017). Although acute and chronic pain have existed for hundreds of years, neurologists and geneticists argue that the causes and treatments of each has changed due to current life circumstances (Baumbauer et al., 2017).

Researchers have been inconsistent in the use of chronic pain terminology in the research literature, which creates a limitation in establishing the knowledge base and recommends the use of *RMD* for chronic pain not directly related to cancer (Heijde et al., 2018). The members of the European League Against Rheumatism and the American College of Rheumatology have reported that RMD symptomology includes pain and limited functioning that can be caused by over 200 different diagnoses; rheumatoid arthritis is the most recognized and prevalent (Heijde et al., 2018). Physicians have described rheumatoid arthritis as a progressive disease characterized by pain and associated emotional, social, financial, and societal burden (Flurey et al., 2017). The psychological aspects of the burden involve depression, anxiety, hopelessness, and fatigue (Al-Fadl et al., 2014; Katz et al., 2016; Naushad et al., 2018). The specialists involved in the European League Against Rheumatism and American College of Rheumatology report that severe RMD can cause disability, decrease quality of life, and decrease life expectancy (Heijde et al., 2018).

Physicians might use a biopsychosocial treatment model to determine the cause of the pain starting with a biomedical focus including X-rays, MRIs, and medications (Schatman, 2015). The patients experience a long and frustrating process because multiple tests only rule out potential causes rather than offer a clear diagnosis and subsequent treatment (Hansen & Bjerrum, 2016). Physicians also might become frustrated with the process and begin to focus on potential psychosocial causes of the chronic pain (Toye et al., 2018).

Hopelessness

Patients express feelings of hopelessness and disappointment after complying with the medical regimen and frustration that the pharmacological treatments did not adequately relieve the pain (Crowe et al., 2017). Experiences of pain can be affected by cultural context (Cagle & Bunting, 2017). Black and Latino patients are significantly statistically more likely to report feelings of hopelessness and stoicism related to treatment of the symptoms of chronic pain than white patients (Robinson-Lane & Vallerand, 2017; Turner et al., 2017).

Older people with non-malignant chronic pain report suspicion regarding potential addictive properties and side effects of the medication (Hansen & Bjerrum, 2016). The patients might settle for less relief of the pain and not explain to the physician that the treatment is not sufficient (Cagle & Bunting, 2017). Patients born before 1948 admire self-reliance and express stoic attitudes when needing help from a physician (Crowe et al., 2017). Patients' fear and disappointment can lead to an increase in the severity of pain and a decrease in quality of life (Duenas et al., 2017).

Depression

Researchers question whether hopelessness and depression occur together or separately (Hansen & Bjerrum, 2016). Fiest et al. (2017) reported that 66 % of patients diagnosed with rheumatoid arthritis, one of the specific causes of RMD, are likely to experience depression. The presence of depression strongly predicts work disability in patients diagnosed with early onset RMD (Englebrecht et al., 2017). Patients report confusion regarding whether the depression increases the severity of feelings of pain or the pain increases the depression (Katz et al., 2016; Naushad et al., 2018). Fiest et al. (2017) reviewed 1291 abstracts regarding pharmacological and psychological treatments for depression in patients diagnosed with rheumatoid arthritis and could not find evidence of an intervention that resulted in a statistically significant decrease in depression symptoms.

Anxiety

Patients diagnosed with RMD might experience anxiety while experiencing depression (Katz et al., 2016). Anxiety is defined as persistent excessive worry or fear that can include feelings of being overwhelmed (Pitcher et al., 2019). Fiest et al. (2017) reported that 70% of patients diagnosed with rheumatoid arthritis are likely to experience anxiety which can affect patients' coping abilities and quality of life. Patients report feeling anxious regarding the possibility of other people labeling the patient as weak also called stigma (Toye et al., 2018). Male patients reported feelings of loss of power and control which was a challenge to masculine identity (Flurey et al., 2017). RMD can cause a decrease in strength and agility (Matcham et al., 2015). Patients reported withdrawing from social experiences and pleasurable activities due to the anxiety (Duenas et al., 2016). Researchers postulated that patients’ feelings of depression, anxiety, and fatigue can be interrelated, while practitioners hypothesized a need to examine each symptom separately (Al-Fadl et al., 2014).

Fatigue

Fatigue can be caused by a lack of sleep or severe stress in the average population; however, 80% of patients diagnosed with RMD report fatigue (Matchem et al., 2015; Santos et al., 2019). Medications prescribed to reduce chronic pain frequently have side effects of fatigue (Fiest et al., 2017). Fifty seven percent of patients report that fatigue is the most debilitating aspect of rheumatoid arthritis (Matcham et al., 2015). Fatigue can be affected by obesity, sleep disturbances, and decreased physical exercise found in research regarding patients diagnosed with RMD (Katz et al., 2016). Matcham et al. (2015) systematically reviewed literature regarding fatigue in patients diagnosed with RMD and found that an increase in fatigue was consistent with increases in depression and severity of pain. Patients’ need for assistance with ADLs increased as levels of fatigue increased (Crowe et al., 2017).

Medical and Nonmedical Treatment Options for RMD

Physicians might treat the symptoms of pain, fatigue, depression, and anxiety separately or concurrently (Jonas et al., 2019). Treatments might include prescribing medications or referral to a mental health provider, or both (Dures et al., 2014; Jonas et al., 2019). Physicians report frustration regarding the empirical evidence for successful treatment options regardless of the biopsychological focus of the treatment (Schatman, 2015). The next section includes an overview of possible medical and nonmedical treatments to reduce patients' symptoms of RMD.

Medical Treatment Options

Physicians can use pharmaceutical or surgical options for the medical treatment of chronic pain (Toye et al., 2018). If a clear physiological cause of the pain exists, surgeons might recommend an invasive procedure to replace the damaged joint causing the chronic pain with significant potential success (Jonas et al., 2019). Jonas et al. (2019) warned that surgeons are also recommending invasive procedures without a clear anatomical cause resulting in unsuccessful outcomes.

The medications prescribed to reduce symptoms of RMD might include non-steroidal anti-inflammatory drugs (NSAIDs including ibuprofen, naproxen, and aspirin), acetaminophen (Tylenol), antidepressants (for sleep problems causing pain), anti-seizure medications (assists with nerve damage), and steroids (dexamethasone and prednisone to decrease inflammation) (Baumbauer et al., 2017; Jonas et al., 2019). In treatment for chronic pain, physicians recommend comparing the potential benefit of a treatment to the risk for adverse outcomes, including addiction and death (Andrews et al., 2017; Jonas et al., 2019). Physicians reported that opioids, including morphine, codeine, fentanyl and methadone, are considered safe for the patient when properly used under supervision (Pitcher et al., 2019). Fiest et al. (2017) systematically reviewed randomized controlled clinical trials of antidepressants and other pharmacological treatments for depression in patients diagnosed with RA and did not find statistically significant results of improvement. The next section includes an overview of nonmedical treatment options for patients diagnosed with RMD.

Nonmedical Treatment Options

Patients expect to have choices regarding the use of medical or nonmedical treatments, as well as a combination (Jonas et al., 2019). Toye et al. (2019) surveyed physicians managing chronic pain in clinical settings who reported barriers to accessing nonmedical treatment options including educational programs, counseling, support groups and physical activity programs. Physicians also reported being unaware of potential nonmedical resources in the community and efficacy in reduction of symptoms of RMD (Toye et al., 2019). The subsequent paragraphs include information regarding educational programs, counseling, support groups, and physical exercise programs.

Patients can acquire knowledge regarding assessment and relief of the symptoms of RMD through educational programs which can increase compliance with prescribed treatments (Cagle & Bunting, 2017). Physicians might refer patients to case management services which disseminate information regarding the disease process and potential treatments (Turner et al., 2017; Schatman, 2015). Mental health practitioners offer Cognitive Behavioral Treatment (CBT) which can be successful at assisting patients diagnosed with RMD (Baumbauer et al., 2017; Cagle & Bunting, 2017). The practitioners report that CBT can be used to address faulty or inaccurate thinking regarding the disease diagnosis, issues of locus of control and coping strategies (Dures et al., 2014). Hearn et al. (2019) found inconclusive results regarding the effectiveness of CBT in a population of patients diagnosed with RA.

Support groups for patients diagnosed with RMD can be helpful in reducing the symptoms of RMD, including depression, hopelessness, fatigue, and anxiety (Ventura & Chung, 2019). Flurey et al. (2017) posited that men diagnosed with RA are open to participation in a support group if the primary activity is not exclusively discussing feelings and the facilitator's stated purpose is clear. Topics to be discussed might include successful coping strategies, helpful exercise programs, and meditation techniques (Flurey et al., 2017).

Patients participating in physical exercise programs have experienced positive effects related to a decrease in chronic pain (Baumbauer et al., 2017; Katz et al., 2016). Patient's participation in physical therapy and exercise programs can decrease frailty and obesity which affects the negative consequences of chronic pain (Andrews et al., 2017). Patient participation in yoga or other low impact exercises are strongly correlated with increases in quality of life and decreases in depression and anxiety (Hearn et al., 2019). Mental health providers have reported success for patients diagnosed with RMD in mindfulness therapy, which is a practice of accepting the current moment, here and now, instead of attempting to change the internal and external experiences (Hearn et al., 2019). Other treatments that might be helpful to patients are meditation and biofeedback (Dures et al., 2014; Schatman, 2015). Practitioners involved in interdisciplinary pain management programs use a variety of medical and nonmedical treatment options mentioned in the previous paragraphs.

Interdisciplinary Pain Management Programs

Evidence exists to support the use of interdisciplinary pain management programs in treating the biological, psychological, and social aspects of RMD with a combination of medical and nonmedical treatment (Schatman, 2015). Interdisciplinary pain management programs can include a physician, nurse, mental health practitioner, occupational therapist, physical therapist, and vocational counselor (Hansen & Bjerrum, 2016; Schatman 2015). The potential health care provider participants vary in rural and urban medical settings (Morelli et al., 2019; Potter et al., 2017). Their roles might expand to include a wider variety of mental health treatment services due to the decreased availability of health care practitioners in rural areas with expertise in RMD (Morelli et al., 2019; Potter et al., 2017). For example, a rheumatologist might include cognitive behavior treatment services in a clinic appointment to assist the patient in treatment of fatigue or depression (Koster et al., 2017; Santos et al., 2019). A social worker might include nutrition education in a hospital discharge plan to assist the patient in treatment regarding depression (Katz et al., 2016).

Researchers have documented the effectiveness of interdisciplinary pain management treatment for decades and advocated for policy changes to financially support the implementation (Schatman, 2015). Health insurance agency personnel have attempted to adapt interdisciplinary pain management programs to include only the physician, nurse, and physical therapist in the service with inadequate results (Schatman, 2015). Qualitative researchers have examined patients’ perceptions of satisfaction in these services and quantitative researchers have examined increased positive medical outcomes including reduced hospital admission recidivism, compliance with medical treatment, and nursing home placement (Betini et al., 2017; Crowe et al., 2017; Dures et al., 2017; Toye et al., 2018). I could not locate any research that examined the caregivers' perceptions of their loved ones' interdisciplinary pain management treatment (Lynch, 2017). In the next section, I will offer information about caregiving in general, beginning with a brief historical overview of caregiving.

Caregiving

The following literature review sections will focus on the concept of caregiving and what is known about caregiving. An overview of caregiving from a historical perspective. Then the caregivers' role in the patient's treatment.

During antiquity, adults needing assistance with activities of daily living (ADLs) have required the assistance from family caregivers (Macon, 2016; McDermott & Mendez-Luck, 2018). Out of a feeling of obligation, family members often took on this role (Kleinman, 2015). Asian and African tribal members supported caregiving as a valued aspect of worship (Kleinman, 2015). Throughout history in Islamic, Jewish, and Christian traditions, individuals continued to be caregivers out of a sense of sacrifice, a duty to honor goodness, and restore morality (Kleinman, 2015; McDermott & Mendez-Luck, 2018). Religious leaders pressured their followers in aspects of caregiving relative to salvation (Kleinman, 2015; McDermott & Mendez-Luck, 2018).

Prior to the *Elizabethan Poor Relief Act of 1601*, caregivers could independently decide whether to bend to this pressure (Macon, 2016). In England, the Parliament passed the initial filial responsibility laws to decrease the burden on the government to fill in the gap where family members could not or would not assist the individuals needing assistance with ADLs (Macon, 2016). Without the informal nonpaid caregivers, the individuals might starve, become significantly ill, and possibly die (Balintona, 2018).

In the late 18th century, the United States government followed the English example in laws regarding filial responsibility (Macon, 2016). The combined coercing of the religious and governmental authorities to require that the family members become caregivers and diminish the burden posed very effective (Balintona, 2018).

From the 19th century and onward, a significant portion of the population in the United States began moving to urban areas due to improvements in clean water, sanitation, and medical technology (Kleinman, 2015). The number of individuals needing assistance with ADLs changed in proportion to the number of family members available to be caregivers (Macon, 2016). Women began to leave caregiving activities at home for paid employment (Corvin et al., 2017). In 1935, U.S. Congress passed the *Social Security Act* to affect the public policy regarding financial incentives to take care of the elderly (Balintona, 2018). In 1965, U.S. Congress passed *Title XVIII of the Social Security Act* to create Medicare and Medicaid which are programs offering skilled and nonskilled caregiving services (Macon, 2016).

In the previous section, I offered information regarding a historical overview of caregiving in general. Caregivers report that they want to help their loved ones with their ADLs while also learning about the diagnosis and treatment (Todorova et al., 2016). Researchers attempt to learn about caregiving by quantitatively looking at the characteristic of dyads that seem to result in positive outcomes for the patient or that seem to result in negative outcomes for the caregiver (Jokogbola et al., 2018). Specifically, researchers have examined the types of responses that caregivers might offer to assist a patient and how each might affect the concept of patient well-being. The next section includes information about the different types of caregiver responses and then about how those might affect patient well-being.

Caregivers' Responses

The responses of a loved one to the patient's needs could be problematic, solicitous, or empathic (Beggs et al., 2015; Gere et al., 2015; Hemphill et al., 2016). Problematic support is support that is not needed or that does not match the patient's needs (Crespo & Fernandez-Lansac, 2014; Hemphill et al., 2016; Lawton et al., 1989; Uysal et al., 2017). Examples of this might include being angry at the patient because they do not take their medication as prescribed or do what the doctor recommended (Crespo & Fernandez-Lansac, 2014; Schulz et al., 2017).

Researchers included caregivers in their sample regarding cancer and found that solicitous responses occur when the caregiver is extremely anxious or apprehensive about the patient's health and well-being (Hemphill et al., 2016; McGilton et al., 2018). The caregiver's concern might be excessive and result in criticizing the patient for attempting to participate in activities that they enjoy, including gardening or taking a walk (Helgeson et al., 2018). The patient might consequently have feelings of depression or hopelessness affecting well-being (Beggs et al., 2015; Englbrecht et al., 2017; Ojeda et al., 2014). Subsequently, the patient might experience an increase in the severity of symptoms (Duenas et al., 2016; Hemphill et al., 2016; Ojeda et al., 2014).

An empathetic response from a caregiver occurs when the caregiver attempts to match the offered level of assistance with the patient's level of need for assistance (Gere et al., 2015; Hemphill et al., 2016). The caregiver is motived by a desire to increase the patient's well-being and not to punish them (Hemphill et al., 2016; Schulz et al., 2017). The caregiver gives consistent messages of belief that the patient is competent and capable of meeting their own needs (Gere et al., 2015). The caregiver offers messages of autonomy in determining the level and type of the patient's need for assistance (Gere et al., 2015). Finally, the caregiver shows availability for assistance due to concern about the patient's well-being as a part of the relationship and accomplishment of a team goal for success (Helgeson et al., 2018; Todorova et al., 2016). The patient might report that the caregiver expresses understanding about the situation (Helgeson et al., 2018).

The response of the caregiver might affect a patient's adoption of unhelpful coping strategies (Beggs et al., 2015; Crespo & Fernandez-Lansac, 2014; Uysal et al., 2017). When caregivers respond by excessively providing options to the patient regarding problem solving and accomplishing ADLs, the patient might feel hopelessness (Helgeson et al., 2018; Uysal et al., 2017). The caregiver might respond with confidence regarding the patient's self-efficacy and ability to complete ADLs resulting in autonomy, support, and well-being (Gere et al., 2015; Hemphill et al., 2016). The caregiver might attempt to understand the patient's perspective or encourage an attitude that the dyad is a team working together to cope with the chronic pain diagnosis resulting in patient well-being (Gere et al., 2015; Todorova et al., 2016). Much research focused on the previously discussed caregivers' responses focused on the patients' perception of how it affected their well-being (Beggs et al., 2015; McGilton et al., 2018; Uysal et al., 2017). In the next section, I will offer information regarding literature about patients' well-being, in general, relative to caregivers' responses.

Patients' Well-Being

Well-being is directly related to the accomplishment of three basic psychological needs specifically autonomy, competence, and relatedness (Berry et al., 2017; Dures et al., 2016; Flurey et al., 2017). Autonomy is engaging in volitional activities and acting in accordance with one's authentic self (Crowe et al., 2017; Flurey et al., 2017). Competence is feeling capable, self-efficacious, and optimally challenged (Dures et al., 2016; Flurey et al., 2017). Relatedness is having a sense of belonging and feeling genuinely connected to others (Berry et al., 2017; Dures et al., 2016; Flurey et al., 2017).

The level of caregiver's support for autonomy predicted an increase in the patient's satisfaction of basic psychological needs (Helgeson et al., 2018). Patient's satisfaction with the level and type of assistance regarding ADLs is correlated with the patient's perception of too much or too little help (Gere et al., 2015). Patient's well-being increased as the fit or match increased between the patients perceived need level and the patient's perception of the caregivers offer of assistance (Gere et al., 2015). As the patient's pain level increased, the patient's well-being decreased but the reverse is not supported in the empirical evidence (Beggs et al., 2015; Duenas et al., 2016; Dures et al., 2016; Uysal et al., 2017).

Matching the Caregivers' Assistance to the Patients' Level of Need

Caregivers might need information from health care providers, specifically social workers in medical settings, to accurately assess a patient's ability to accomplish ADLs (Da Silva Barreto et al., 2018; Hemphill et al., 2016; Uysal et al., 2017). If caregivers were told of medical recommendations including restricted activities, caregivers might adjust the response regarding the type of assistance offered (Hemphill et al., 2016; Uysal et al., 2017). A problematic or punishing response might result from a caregiver's belief that cooking is a restricted activity rather than a medically approved activity (Cagle & Bunting, 2017; Uysal et al., 2017). Caregivers might assume that patients should not do pleasurable activities, such as cooking (Duenas et al., 2016; Dures et al., 2016). If a mental health provider in a medical setting offers only general information to caregivers regarding a diagnosis rather than the specific patient's level and type of need, caregivers might struggle in offering an empathic response (Cagle & Bunting, 2017; Da Silva Barreto et al., 2018; Dures et al., 2016). The caregiver's confidence in the patient's ability to manage the symptoms of the diagnosis might increase from the information (Da Silva Barreto et al., 2018; Hemphill et al., 2016).

Berry et al. (2017) completed a systemic review of effectiveness of couples' interventions on the psychological consequences of chronic pain and found that two thirds of the research included in the review did not include feedback from the caregiver. Interventions included educationally based treatment programs involving case management services, exercise programs, nutrition services, and counseling related to coping, stress reduction and intimacy (Berry et al., 2017). Numerous researchers recommend including the caregiver in the patients' treatment and asking them for feedback regarding efficacy of the treatment (Duenas et al., 2016; Hansen & Bjerrum, 2016; Hawamdeh et al., 2017; Jokogbola et al., 2018; Lynch, 2017).

The previous section offered information regarding types of caregiver responses and how each might affect patient well-being. The inclusion of the caregiver in the treatment planning and implementation for the patient could be beneficial (Duenas et al., 2016; Hansen & Bjerrum, 2016; Hawamdeh et al., 2017; Jokogbola et al., 2018; Lynch, 2017). The next section will include information regarding an overview of the role of caregivers in health care treatment.

Caregivers' Role in Treatment

The inclusion of the caregiver in the treatment planning and implementation for the patient could be beneficial (Duenas et al., 2016; Hansen & Bjerrum, 2016; Hawamdeh et al., 2017; Jokogbola et al., 2018; Lynch, 2017). Researchers have recently recognized the extent to which caregivers are expected to assist their loved ones with intense and complex nursing tasks (Lynch, 2017; Reinhard & Young, 2019). Health care providers are financially compensated by health insurance companies for teaching caregivers how to do wound care, physical therapy, catheterization, medication distribution, and remove stitches (Reinhard & Young, 2019). I could not locate any research that examined the caregiver's perceptions of involvement in wound care, catheterization or removal of stitches. Specific to a diagnosis of RMD, caregivers are increasingly being asked to provide assistance with collecting urine, feces or blood testing specimens from the patient and assist with physical therapy treatment, however minimal research includes the perceptions of caregivers in assisting with these intense and complex nursing tasks (Lynch, 2017; Reinhard & Young, 2019; Shugrue et al., 2019; Vaughan & Kluger, 2018). The following section will include information from research that was focused on the health care providers' perspective.

Patients living with cancer, dementia and other chronic illnesses experience physical and psychological difficulties in meeting the demands of daily living (Crespo & Fernandez-Lansac, 2014; Duenas et al., 2016). The caregivers are also affected by the difficulties faced by their loved ones (Berry et al., 2017; Crespo & Fernandez-Lansac, 2014; Duenas et al., 2016). Caregivers might assist the patients with ADLs including obtaining treatment services such as scheduling medical appointments, physical therapy, and counseling (Berry et al., 2017; Crespo & Fernandez-Lansac, 2014). Caregivers might experience dual roles as the primary providers of support to patients regarding ADLs and as family members who need assistance and support with the stress resulting from the situation (Cagle & Bunting, 2017; Crespo & Fernandez-Lansac, 2014; Duenas et al., 2016; Gamarel & Revenson, 2015).

Experiences of caregivers of patients diagnosed with dementia have been qualitatively examined regarding caregiver burden, challenges, and stigma (Jokogbola et al., 2018; Todorova et al., 2016). Researchers found that these caregivers attempt to educate themselves regarding the patients' diagnosis through communication with health care professionals or searching the internet (Jokogbola et al., 2018; Nowakowski & Sumerau, 2017; Todorova et al., 2016). Their experiences included feelings of frustration, intimidation and confusion in attempting to advocate for their loved ones and depersonalization from health care providers (Jokogbola et al., 2018; Todorova et al., 2016). Caregivers expressed a desire for the health care provider to include them in the patients' mental health treatment, specifically through decision making, education, and support (Jokogbola et al., 2018; Nowakowski & Sumerau, 2017; Todorova et al., 2016). I was unable to locate research findings based on data from caregivers of patients diagnosed with RMD, but I will offer an overview of the literature based on the health care providers' and patients' perspective of the caregiver's involvement in treatment.

Health Care Providers' Experiences of Caregivers' Involvement

Specific to patient diagnosed with RMD, researchers have qualitatively examined the concept of caregiver involvement by collecting data from the health care provider's perspective in a multidisciplinary rehabilitation program (Hansen & Bjerrum, 2016). Results included increased positive effects of pain management and level of functioning for the patient and supported the inclusion of caregivers in treatment (Hansen & Bjerrum, 2016). However, the researchers acknowledged a need to examine caregivers' perceptions of their involvement in pain management services for their loved ones, specifically regarding access to mental health services, communication with the health care providers and support (Hansen & Bjerrum, 2016).

Summary

The practice of caregiving by family members has existed throughout history (Kleinman, 2015; Macon, 2016). Caregivers of loved ones diagnosed with chronic pain assist patients with ADLs, including accessing mental health treatment services, communicating with health care providers, and receiving support (Nowakowski &

Sumerau, 2017). Research supports the inclusion of caregivers of patients diagnosed with RMD in medical and nonmedical treatments for the patient, but a lack of empirical evidence was found regarding the caregivers' experiences of being included (Berry et al., 2017; Nowakowski & Sumerau, 2017; Todorova et al., 2016). Chapter 2 includes a synopsis of the strategy used to search the relevant literature and a review of the literature examined. I used the review and synthesis of peer reviewed journals and other empirical literature related to the subject of the study to assist the planning of the proposed research in accordance with the hermeneutical phenomenological conceptual framework. Chapter 3 includes the strategy used for the research design, rationale, and role of the researcher. Chapter 3 also contains information about the methodology including the plan for participant selection, recruitment, and ethical considerations. Finally, Chapter 3 includes a description about the instrumentation, data collection, analysis, issues of trustworthiness, and ethical issues of the study and mechanisms to mitigate ethical concerns.

Chapter 3: Research Method

Introduction

For this hermeneutical phenomenological study, I explored the shared lived experiences of female caregivers (between the ages of 65 and 70) of patients diagnosed with chronic pain from RMD in terms of involvement with their loved ones' mental health care treatment. To address the apparent gap in the literature regarding these experiences, I focused on the perceptions of caregivers accessing mental health care services for their loved ones, communicating with their health care providers, and receiving support in medical settings. Caregivers contribute to the patients' well-being by assisting in ADLs, which can subsequently decrease symptoms related to mental health issues such as depression, anxiety, fatigue, and hopelessness (Dures et al., 2016; Lynch, 2018).

Findings from this research may include information constructive to medical social workers in advocating for improvement of provision of services to the caregivers, promote positive social change, and fill a gap in the literature (Reynart et al., 2019). Policy makers might use these findings to address the need for a reduction of indirect, nonmedical expenses as the number of patients diagnosed with chronic pain increases along with their reliance on caregivers (Chari et al., 2015). This chapter includes the research design and rationale, role of the researcher, methodology, data analysis plan, issues of trustworthiness, and ethical considerations. The research question that guided this study was: What are the shared lived experiences of female caregivers (ages 65 to 70) of patients diagnosed with RMD living in the rural Southwestern region of the United

States, specific to their involvement with health care providers of mental health treatment of their loved ones?

Research Design and Rationale

Heidegger (1927) explained that the central concepts of hermeneutic phenomenology include the importance of worldview, language, and an arching process as opposed to a linear process of extending the knowledge base regarding the phenomenon. A number of other research designs exist but alignment of aspects of the study require the use of a hermeneutic phenomenological research design (Moustakas, 1994; Stroh, 2015). Alternative methods considered and rejected for this study include ethnographic and grounded research methods, but hermeneutic phenomenological research emerged as appropriate.

Ethnographic research is a qualitative research methodology used to study perceptions of individuals (Denzin & Lincoln, 1994; Moustakas, 1994). Culture is a central concept of ethnography and requires the acquisition and analysis of extensive descriptions and insights on an ethnic group's worldview (Denzin & Lincoln, 1994; Moustakas, 1994). Researchers might use ethnography in documenting the cultural practices of caregivers of patients diagnosed with chronic pain (Denzin & Lincoln, 1994; Moustakas, 1994). However, the goal of this study was to describe and interpret the caregivers' shared lived experiences of communicating with their loved ones' health care providers.

Grounded theory would not have aligned with the study's research question, purpose, and analysis of the stories in the texts of the caregivers (Denzin & Lincoln, 1994; Moustakas, 1994). Glaser and Strauss (1967), who originated grounded theory, focused on the ability of researchers using a grounded theory design to theoretically explain a phenomenon through social interactions. A research question that would align with grounded theory research might be one that attempts to explain the cause of an individual’s behavior (Denzin & Lincoln, 1994; Moustakas, 1994). This type of study might assist a researcher with understanding the decision-making process of caregivers of patients diagnosed with RMD (Denzin & Lincoln, 1994; Moustakas, 1994).

Moustakas (1994) addressed the need for clarity regarding the logical basis or rationale for choosing one research design over another. I implemented a hermeneutical phenomenological design because I described and interpreted the shared lived experiences of caregivers of loved ones diagnosed with chronic pain. This approach is seemingly optimal in allowing for the importance of interpretation of the essence of the phenomenon through the analysis of text provided by caregivers and for the encouragement of the caregivers to express the collective and singular first-person perspective simultaneously (Moustakas, 1994; Stroh, 2015; Sturgess, 2016).

I encouraged participating caregivers to express their perception or essence of the phenomenon of caring for their loved ones. The justification of the research design and purpose provided the foundational framework to understand the aspects of the research methods for this study. In summary, the hermeneutical phenomenological research design used for this study offers the opportunity to describe and interpret the essence of caregivers’ shared lived experiences of involvement in their loved ones’ mental health treatment. Qualitative researchers accept and respond to subjectivity in the research process through attempts to increase the integrity of the research by clearly examining the researcher's involvement in the research (Denzin & Lincoln, 1994).

Role of the Researcher

Through reflection, the hermeneutic phenomenologist attempts to extract new and appropriate meaning from the texts of the participants, replacing the researcher's previous understanding (Denzin & Lincoln, 1994; Moustakas, 1994; Thackeray & Eatough, 2015). Prior to data collection, a researcher might complete an exhaustive literature review required by an institutional review board or other governing bodies (Fry et al., 2017; Sloan & Bowe, 2013). A researcher might learn in the literature review or in personal or professional experiences about aspects of the phenomenon that influence decisions regarding interpretation of the data (Edwards, 2019; Fry et al., 2017). A phenomenological researcher is the sole instrument of inquiry and data collection (Denzin & Lincoln, 1994; Stroh, 2015). The detrimental effects of the potential for a researcher to acquire an attitude that is closed to different worldviews might be weighed against the ethical necessity to undertake rigorous standards (Fry et al., 2017; Spence, 2017).

Interpretive researchers, including Gadamer and Heidegger, theorized that disclosing researcher biases related to the phenomenon of study supports the ability of the consumers to critically evaluate the effect of the subjectivity on potential outcomes of the study (Moustakas, 1994; Sturgess, 2016). Husserl described a researcher's attempt to abstain from preconceived ideas and prejudices resulting in decreased subjectivity and recommended the use of bracketing to accomplish thought revision (Husserl, 1931;

Moustakas, 1994). Hermeneutical researchers do not support the use of bracketing due to the acceptance that biases occur simultaneously within the circular process of creating authenticity (Stroh, 2015).

As the sole researcher in this phenomenological research, I was the primary data collection instrument of inquiry for the study (Denzin & Lincoln 1994; Moustakas, 1994). My role and responsibilities included recruiting caregivers of patients diagnosed with RMD who met the inclusionary criteria. I then conducted semistructured interviews using a framework of open-ended questions established prior to the interviews. I attempted to consistently use the framework in the interviews to elicit detailed text. I recorded, transcribed, and analyzed the information offered by the caregivers, specifically the language used and stories told (Fry et al., 2017).

In this section, I acknowledge my specific personal and professional lived experiences relative to the proposed research question. During the 15 years I worked as a social worker in medical settings, I provided counseling and assessment services to patients diagnosed with RMD and their caregivers. I also have personal experience as a caregiver for my husband who has been diagnosed with RMD. Living in a rural area of the Southwestern United States, I have friends who have been caregivers or require assistance with ADLs from a caregiver. As a researcher, I might have a professional or personal relationship with the health care providers who have interacted with the participants through provision of mental health care treatment to their loved ones. A power imbalance might exist between the participants and me due to the general presumption or preconception that a researcher, specifically one with social worker credentials, has more expertise than the participant answering the researcher’s questions. The participant might view me as a professional expert or as a member of the same cohort who can relate.

Biases based on a researcher’s prior beliefs or preconceptions can impact data collection and analysis in research (Fry et al., 2017; Thackeray & Eatough, 2015). As a phenomenological researcher, my preconceptions might come from personal or professional experiences with caregivers or individuals diagnosed with RMD (Denzin & Lincoln, 1994; Moustakas, 1994). Biases might also result from experiences of family members who have similar preconceptions regarding the phenomenon (Denzin & Lincoln, 1994; Moustakas, 1994).

I am aware that I have conscious and unconscious preconceptions and biases that could affect how I collect and interpret texts regarding the phenomenon. I tried to be aware of the intersubjectivity that naturally occurs in phenomenological research. I disclosed my personal and professional experiences relative to the phenomenon to the participants and to the consumers of my research. I attempted to be open minded and curious regarding each participant’s lived experience.

As the sole researcher in this study, I attempted to manage personal opinions and biases while focusing on allowing the emerging truths to surface through the perspective lens of caregivers of loved ones diagnosed with RMD. I attempted to minimize the potential effects of an imbalance in power through informal discussion and the use of a formal consent process. I encouraged caregivers regarding the decision to participate and ability to withdraw at any time with no recrimination.

I acknowledge that my personal experiences of being a caregiver to a loved one who has been diagnosed with RMD might be similar to the experiences of the participants, but I also understand that at various times in the research process, the meanings may diverge (Moustakas, 1994). I acknowledge a possible bias due to my experience working with caregivers in the Southwestern region of the United States over numerous years. I tried to put my biases in the forefront and disclose the nature of my interest in further exploration of this phenomenon with participants.

Methodology

Participant Selection Logic

Qualitative researchers use many different sampling strategies to select information-rich data in the process of inquiry (Denzin & Lincoln, 1994; Moustakas, 1994). Phenomenologists do not support the presumption of a priori sampling, and subsequently are not likely to use the terminology referring to sampling strategy but are increasingly likely to use the terminology referring to the method of choosing a sample (Denzin & Lincoln, 1994; Miles et al., 2014). I used two methods of choosing a sample to recruit and identify female caregivers of patients diagnosed with RMD: a purposive criterion method and a snowball sampling method. I used the inclusion criterion of an age range of 65 to 70 and participants who live in the rural Southwestern region of the United States.

Hermeneutic phenomenologists support a connection between the experiences of a researcher and the experiences of the participants (Heidegger, 1927). I chose the inclusion criteria of female caregivers living in the rural Southwestern region of the

United States because I am a female caregiver living in the rural Southwestern region of the United States. I chose the age range of 65 to 70 because some caregivers work outside the home and the decision to retire might occur during this age range (Chari et al., 2015). I did not exclude individuals based on whether they were employed outside the home or only inside the home.

I used purposive criterion sampling to attempt to uncover insights into the phenomenon that would yield an in-depth understanding of the caregivers' shared lived experiences. Researchers endeavor to create rigorous inquiry and require that the process of participant selection is clear and could be replicated by other researchers (Denzin & Lincoln, 1994: Miles et al., 2014; Moustakas, 1994). I selected participants based on the following inclusion criteria: (a) self-identified as a female caregiver of a family member diagnosed with RMD, (b) living in a rural Southwestern region of the United States, (c) between the ages of 65 to 70, (d) English speaking, (e) willing to participate in a recorded interview lasting 1 hour or less, and (f) granting the researcher the right to use the text in completion of the dissertation. One of the reasons I focused on recruiting female caregivers was because, according to the National Alliance for Caregiving and AARP Public Policy Institute (2015), a cultural expectation exists for women in the Southwestern region of the United States to fulfill caregiving responsibilities in their families, resulting in a larger percentage of female family caregivers than male family caregivers.

Snowball sampling occurs when a researcher requests that a participant who is acknowledged to meet the inclusion criteria to assist in identifying other individuals who meet inclusion criteria to participate in the research study (Lee & Spratling, 2019). Snowball sampling appears to align with the research question in this hermeneutical phenomenological study and is an appropriate technique to limit the selection of participants who meet the predetermined criteria (Heckathorn & Cameron, 2017). I asked identified caregivers if they knew of other caregivers who might meet the inclusion criteria and asked if they were comfortable in either giving them the recruitment announcement (Appendix A) or in asking those individuals to email or call me. I explained to caregivers that this was voluntary and in no way would affect their participation in the research. The use of more than one sampling strategy can increase response rate, especially among caregivers who have time constraints due to caregiving (Wohl et al., 2017).

Initially, I used criterion and snowball methods of sampling to recruit participants by posting fliers on public bulletin boards that do not require permission from anyone to post inviting potential participants to contact me by phone or email (see Appendix A). Second, during the initial contact with potential participants, I explained the purpose, potential benefits, potential risks, inclusion criteria, and voluntary nature of the research project. Finally, I informed participants regarding recruiting other caregivers to contact me should they be interested in the study. I continued the aforementioned referral format until I recruited 12 research participants and reached theoretical saturation.

I interviewed 12 caregivers meeting inclusion criteria. The final sample size was determined by the number of caregivers required to reach the point of theoretical saturation. According to hermeneutical phenomenologists, the sample size cannot be determined a priori; subsequently the number 10 used in my research planning was only an approximation (Moustakas, 1994). Guest et al. (2006) are credited with publishing the seminal reference for reaching data saturation in qualitative research by developing a codebook of themes found in the verbatim transcripts of 60 interviews. Data saturation is usually achieved after between six and 12 interviews (Guest et al., 2006; Hagaman et al., 2017). Starks and Trinidad (2007) also recommend a range between six and 10 interviews for phenomenological studies. I conducted 12 interviews to reach theoretical saturation.

Hermeneutical phenomenologists reported that a smaller sampling size might promote an ability to qualitatively concentrate on the phenomenon or the caregivers' stories of shared lived experiences (Denzin & Lincoln, 1994; Guest et al., 2006; Moustakas, 1994; Thackeray & Eatough, 2015). Phenomenologists use sampling methodologies that require a sample size allowing for theoretical saturation, typically in the range of three to 10 participants (Miles et al., 2014; Thackeray & Eatough, 2015). Previous studies looking at in depth experiences have utilized samples starting at four or five and reach theoretical saturation by five or ten verbatim interview transcripts (Bacon et al., 2020; Low, 2019; Smith et al., 2009; Thackeray & Eatough, 2015). In the iterative process of data collection and analysis, qualitative researchers reported that saturation has occurred when no new information is found in the data or texts (Moustakas, 1994). I conducted 12 interviews consistent with the aforementioned iterative processes until concluding that theoretical saturation had been accomplished due to the finding of no new information in the data.

Instrumentation

For this hermeneutical phenomenological study, I used semi-structured interviews (see Appendix B) to encourage participants to respond with rich, detailed data. Scripted questions organized to be accessible, intentional, and comprehensive can facilitate fluid dialogue in semi-structured interviews (Castillo-Montoya, 2016). Moustakas (1994) reported that informal discussions based around a predetermined set of potential questions can elicit deep, insightful text from participants consistent with hermeneutical research. Focusing on the caregivers' contexts shaping the lived experiences, I used open-ended, in-depth interview questions aligned with the research question to assist the caregivers in telling the story regarding experiences of involvement with the patient's mental health care providers consistent with phenomenological methods. The subsequent sections include a description of the pre-interview procedures, setting of the interviews, and data management process.

Approximately one week before the interviews, I gave the participants a copy of the consent form and interview questions through mail or email (see Appendix C). I called and encouraged the participants to ask questions regarding the consent, research or data collection process. I informed the participants that their involvement in the study was strictly voluntary, and they could withdraw at any time without consequence. If they initially decided to participate, they were still free to withdraw at any time later without any explanation for their decision to withdraw. I provided the participants with the option of conducting the interview over the phone or using web-based technology. All 12 research participants chose to be interviewed over the phone.

At the beginning of the interview, I verified that the participant had no additional questions and signed the consent form or replied “I consent” to the email of the consent form. I asked if the participant was comfortable and ready to begin the interview. I used an audio recorder to record participants’ communication and I informed participants when the recording was beginning. I asked open-ended questions, including probing questions to assist the participants in telling their story. The researcher or participants did not ever express issues with safety or privacy, so I did not stop the interviews. I attempted to determine the risk or presence of distress of the participant during the interview when recalling their caregiving experiences. None of the research participants appeared to show signs of distress during the interview but instead seemed to enjoy talking about their experiences as caregivers. I had potential resources of support for the participant including counseling hotline numbers, community counseling agencies that are willing to provide free counseling to caregivers who might become upset because of thinking about caregiving, or other assistance, but none of the research participants showed signs of needing them.

I recorded the interviews and created a verbatim transcription of each audio recording from the interviews using web based technology which is compatible with telephone call recordings, called Call Recorder. I included notations for pauses, laughter, unintelligible sounds, and other contextual information including observations of reactions and emotions that created rich, detailed data. I emailed a copy of the verbatim transcript to every participant per their preference and asked them to review it for accuracy. Two research participants stated that they did not want to receive the verbatim transcript at all. I also asked them to inform me of specific inaccuracies in the transcript and I made the required changes to the transcripts. Finally, I verified that every participant was in agreement with the final verbatim transcripts to be used in the data analysis.

After I transcribed the audio recordings and obtained member checking for accuracy, I created identifiers for participants to preclude indicating names with the interview content. The digital audio recordings, signed consent forms, raw and revised verbatim transcripts, and data analyses were scanned to an encrypted password protected removable drive. Digital files and paper copies were saved in a locked file cabinet in a locked office where I alone have access. I will destroy the data five years after publication in accordance with Walden University. I informed the participants that Walden's IRB or my committee members could request access to raw data. Additionally, I informed the participants that I am a mandatory reporter and that I am required to breach confidentially in the event of a disclosure regarding harm to self or others related to child and elder abuse. As I did not receive any information from the research participants regarding harm to self or others, I did not inform my dissertation chair, the IRB, and appropriate authorities. I included this information in the informed consent.

Data Analysis Plan

After exporting the data to Excel, I organized and prepared for analysis consistent with Moustakas' (1994) modified Van Kaam method. Using each participant's complete, verbatim transcript, I listed relevant, raw data from the text specific to the experience (Moustakas, 1994). Second, I examined each invariant component regarding indispensability and possibility of abstracting and labeling the component (Moustakas, 1994). I eliminated data that were vague, overlaps, or repetitive. Next, I clustered the labeled themes and then compared each invariant component to the complete, verbatim transcript of each participant by questioning if the invariant component was explicitly included or compatible to the transcript (Moustakas, 1994). I then constructed an individual textural description for each participant using the previously validated components with specific examples (Moustakas, 1994). Based on the individual textural descriptions and imaginative variation, I constructed individual structural descriptions (Moustakas, 1994). Finally, I used the aforementioned invariant components to construct a textural and structural description of the essences of the phenomenon for each participant and subsequently, a composite including the group of participants (Moustakas, 1994).

Issues of Trustworthiness

Researchers strive for quality and rigor in the planning and implementation of research in an attempt to create findings that can be used to explain and describe behavior, solve problems, or affect social change (Moustakas, 1994; Noble & Smith, 2015). Quantitative researchers focus on validity and reliability to establish robust results (Constantinou et al., 2017; Silverman, 2017). Due to ontological and epistemological foundations, qualitative researchers focus on establishing confidence in the truth of the findings or promoting trustworthiness (Constantinou et al., 2017; Sutton & Austin, 2015). Issues of trustworthiness include concepts of credibility, transferability, dependability, and confirmability (Constantinou et al., 2017; Denzin & Lincoln, 1994).

Credibility

Credibility refers to the integrity of the methods used and the extent to which the findings reflect reality (Constantinou, 2017; Noble & Smith, 2015; Sutton & Austin; 2015). Credibility can be promoted by alignment of the research design, methodology, and data analysis (Castillo-Montoya, 2016; Roth, 2015). I developed the proposed research project with a focus on alignment between the hermeneutical research design, the semi-structured interview questions, and the modified Van Kaam data analysis method to encourage credibility. A clear description of the required inclusion criteria, interview protocol, and explanation for support of the establishment of theoretical saturation can impact credibility (Castillo-Montoya, 2016; Constantinou, 2017). Researchers have increased confidence in findings that result from thick, rich data from research participants who possess the inclusion criteria and the ability to describe their experiences (Denzin & Lincoln, 1994; Moustakas, 1994).

I have developed a clear description of the proposed sample's inclusion criteria, specifically regarding rural female caregivers of patients diagnosed with RMD who live in the Southwestern region of the United States to encourage credibility. The use of inclusive criteria provides researchers with a tool for recruiting participants with vital knowledge and experience of the phenomenon to increase credibility of the study (Noble & Smith, 2015; Roth, 2015). The caregivers' ability to communicate with in-depth insight into the phenomenon under investigation could result in thick, rich data resulting in theoretical saturation (Moustakas, 1994; Roth, 2015). To promote credibility, I used verbatim transcripts of the interviews to create thick, rich data.

Transferability

Transferability relates to the applicability of findings in other contexts (Noble & Smith, 2015; Sutton & Austin, 2015). Qualitative researchers might focus on detailed description of the research design, methodology and analysis of the phenomenon under examination and the contexts where the phenomenon occur (Silverman, 2017; Sutton & Austin; 2015). Though I described in explicit detail the study processes, transferability of findings are not generalizable to other populations or contexts. Hermeneutic phenomenological researchers accept the biases that affect researchers' filters through which planning and implementation of a study occurs (Moustakas, 1994). The dialogue between researchers and participants can be affected by the other and might result in findings applicable to a specific context (Noble & Smith, 2015; Silverman, 2017). As the sole researcher, I interacted with caregivers of patients diagnosed with RMD creating a text in simply one specific context. Transferability was affected due to the fact that another researcher might elicit different responses than I might be able.

Dependability

Dependability refers to the consistency employed by the researchers in the study and the ability for other researchers to repeat the study (Constantinou et al., 2017; Sutton & Austin, 2015). To meet this criterion, qualitative researchers can describe the design, methodology, and analysis in specific detail resulting in replicability (Roth, 2015; Silverman, 2017). I have explicitly described the proposed phenomenological research design, methodology, and analysis in specific detail in this chapter to encourage dependability.

By using an interview protocol with intentional, necessary questions, the researchers can assist the participants in responding with thick, rich detail because the experiences are complex and do not neatly unravel (Castillo-Montoya, 2016). Phenomenological researchers attempt to acknowledge researcher bias and utilize ongoing critical reflection of the research methodology to encourage sufficient depth and relevance in data collection (Noble & Smith, 2015). For this hermeneutical phenomenological study, I sought to promote an accurate description of the shared lived experiences of caregivers of patients diagnosed with RMD to promote dependability. Though I used a protocol for interviews to promote dependability in alignment with hermeneutical phenomenological research which could be replicated by other researchers, my findings were not replicable because each researcher is a unique individual.

Confirmability

Confirmability relates to the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest (Denzin & Lincoln, 1994; Sutton & Austin, 2015). Researchers focus on confirmability through detailed documentation of the context of the study, the interview transcriptions, the data analysis and interpretation, and the researchers' own reflections (Roth, 2015; Silverman, 2017). In other types of phenomenology, researchers use member checking or asking the participants to review the transcripts or interpretations for accuracy (Constantinou et al., 2017; Noble &Smith, 2015). I created verbatim transcripts of the interviews and used member checking to encourage confirmability in the data analysis.

Hermeneutical phenomenologists recognize that multiple realities exist and acknowledge that experiences and viewpoints might have resulted in biases and affected clarity and accuracy in presenting participants' perspectives (Moustakas, 1994). I attempted to promote confirmability and to present the meanings that the caregivers of patients diagnosed with RMD offer in the data while simultaneously acknowledging my personal ontology. Also, I shared my potential personal and professional biases to encourage confirmability as mentioned previously in this chapter with the participants throughout the research process.

Ethical Procedures

Researchers in human science use ethical principles to guide the research process and manage potential risks and benefits (Denzin & Lincoln, 1994; Moustakas, 1994). I was guided throughout this study by Walden University's Institutional Review Board Code of Ethics and the National Association of Social Workers Code of Ethics (National Association of Social Workers, 2017). I offered full disclosure of the nature and purpose of the study in the consent form to the caregivers including answering any questions at any time.

The ethical principle of respect for persons focuses on protection of the research participants autonomy while ensuring the disclosure of potential harms and potential benefits (Noble & Smith, 2015). I used a consent form to promote the respect for persons by establish a clear agreement of explicit details regarding what was being asked of them, the potential risks, and potential benefits. I called and encouraged participants to ask questions regarding the research process, consent, or other procedures. Beneficence is defined as the need for research to promote the welfare of the research participants, specifically protection from exploitation and harm(Noble & Smith, 2015). To assist in ensuring beneficence, I informed the participants that their involvement in the study was strictly voluntary and they could withdraw at any time without any explanation. Justice is an ethical principle promoting the fair distribution of burdens and benefits of the research, specifically relative to recruitment of potential research participants (Noble & Smith, 2015). To promote the ethical principle of justice, I attempted to clearly state the rationale for equity in the inclusion criteria I have chosen. This rationale was outlined in the Participant Selection Logic section in this study. I used the inclusion criterion of an age range of 65 to 70 for female caregivers of loved ones diagnosed with RMD living in the rural Southwestern region of the United States. I used this criterion because a cultural expectation exists for woman to be caregivers for their family members requiring assistance with ADLs living in the Southwestern region of the United States and men to assist financially (Bom et al., 2019; Brenna et al., 2014; DiNovi et al., 2015).

I informed the participants that I recorded the interview which was saved on an encrypted password protected removable drive. The signed consent forms and interview transcripts were also scanned to the encrypted password protected removable drive. I assigned a code for each caregiver to protect any identifying information and confidentiality. Digital files on the removable drive were saved in a locked file cabinet in a locked office where I alone have access. I will destroy the data five years after publication in accordance with Walden University. I informed the participants that Walden's IRB or my committee members could request access to raw data. Additionally, I informed the participants that I would breach confidentially in the event of a disclosure regarding harm to self or others related to child and elder abuse.

Summary

I conducted a hermeneutical phenomenological research study to examine the shared lived experiences of caregivers of patients diagnosed with RMD. I used semi-structured interviews to gather data that I analyzed through a modified Van Kaam data analysis. Chapter four includes information regarding the setting and demographics of the participants. Chapter four also includes information regarding data analysis, and evidence of trustworthiness, as well as findings and results of the research study.

Chapter 4: Results

Introduction

I conducted a hermeneutical phenomenological research study to explore the lived experiences of caregivers of loved ones diagnosed with RMD specific to their involvement with their loved ones' health care providers of mental health treatment. I collected data by interviewing 12 caregivers over the phone. I developed semistructured interview questions to gather information from the participants to answer the research question. I analyzed the data using a modified van Kaam strategy resulting in themes or a composite of the textural and structural descriptions of the essences of the phenomenon for each participant. In this chapter, I include the purpose of the study, the research question, the setting, demographics of the participants, and the findings. I also include information regarding issues of trustworthiness and ethical considerations.

For this hermeneutical phenomenological study, I explored the shared lived experiences of female caregivers (between the ages of 65 and 70) of patients diagnosed with chronic pain from RMD in terms of their involvement with mental health treatment professionals, including physicians, psychologists, and social workers working in medical settings. To address a gap in the literature regarding these experiences, I focused on the experiences of female caregivers' involvement in accessing information and support from mental health care providers in medical settings. In response to the increasing number of patients diagnosed with RMD requiring assistance with ADLs, these caregivers contribute to patients' ability to avoid expensive paid assistance and to stay in a preferred housing environment (Milano, 2017; Morelli et al., 2019; Shugrue et al., 2019). Findings from this research can be constructive to medical social workers in advocating for improvement of interactions with caregivers and will help fill a gap in the literature (Reynaert et al., 2019). Policy makers might use these findings to address the need for a reduction of indirect, nonmedical expenses as the number of patients diagnosed with chronic pain increases along with their reliance on caregivers (Chari et al., 2015; Shugrue et al., 2019). The research question that guided this study was: What are the shared lived experiences of female caregivers (ages 65 to 70) of patients diagnosed with RMD living in the rural Southwestern region of the United States, specific to their involvement with health care providers of mental health treatment of their loved ones?

Setting

Data were collected through semistructured interviews that were conducted during the COVID-19 pandemic, which affected many aspects of people's lives. Although all participants lived in the Southwestern region of the United States, through the course of the field work in this study, vaccine clinics were open and mandatory mask wearing and social distancing directives were being relaxed. Women between the ages of 65 and 70 had opportunities to schedule an appointment for a vaccine, but a lack of consensus existed regarding the safety and efficacy of the vaccine. Many people had lost their jobs and were grieving the loss of life prior to the pandemic. The need for mental health treatment increased due to the stresses of the experiences of the pandemic (Pfefferbaum & North, 2020). The extent to which these additional stresses affected participants or the data gathered in the interviews is unknown. Several participants offered information regarding whether they had been vaccinated and whether their loved ones had been vaccinated.

All interviews were conducted over the phone and participants were primarily at their homes during their interview. Whether this setting increased the likelihood of their loved ones listening to their conversation or affected the responses given is unknown. One participant specifically stated her loved one was busy doing something during the interview, but she wanted to go into another room so he could not overhear our conversation.

Demographics

A recruitment email announcement (see Appendix A) was sent to all potential participants. Previous discussions either on phone or in person occurred between all participants and me to encourage clarity as to the purpose of the study and expectations of the participants, including inclusion criteria. Several participants asked questions regarding the definition of *caregiver*. Three participants stated they did not think of themselves as a caregiver, but one stated they did all the driving for their loved one and another stated that her loved one could drive but could not remember to take his medication without her assistance. The third participant said she assists her loved one with ADLs, but he is not disabled. I answered all questions regarding the definition of caregiver used in the dissertation and explained they were free to not participate if they did not feel they were caregivers. Given the additional information, all participants self-identified as caregivers. Prior to the interview beginning, all participants indicated they met the inclusion criteria, specifically: (a) self-identified as a female caregiver of a family member diagnosed with RMD, (b) living in a rural Southwestern region of the United States, (c) between ages 65 and 70, (d) English speaking, (e) willing to participate in a recorded interview lasting 1 hour or less, and (f) granting me the right to use the text in completion of the dissertation. The participant profiles are, as follows:

- P1 was a female caregiver for her brother who was diagnosed with psoriasis, vertigo, and arthritis/RMD. She was not employed at the time of the interview. P1 stated that she assisted her loved one with ADLs, including driving, medication distribution, cooking, and communicating with the health care provider. She reported that her brother has been diagnosed with depression. She reported that she lives in a rural region in Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.
- P2 was a female caregiver for her husband who was diagnosed with knee pain, memory loss, and chronic pain/RMD. She was not employed at the time of the interview. P2 stated that she assisted her loved one with ADLs, including driving, medication distribution, cooking, wound care, and communicating with the health care provider. She reported that her husband has been diagnosed with depression. She reported that she lives in a rural region in Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.
- P3 was a female caregiver for her son who was diagnosed with liver disease and chronic pain/RMD. She was not employed at the time of the interview. P3 stated that she assisted her loved one with ADLs, including driving, medication distribution, cooking, cleaning, and communicating with the health care provider.

She reported that her son has been diagnosed with depression. She reported that she lives with her son in a rural region in Colorado. She did not tell me her exact age but agreed that she met all inclusion criteria.

- P4 was a female caregiver for her husband who was diagnosed with diabetes and arthritis/RMD and had undergone amputation of his leg. She was not employed at the time of the interview. P4 stated that she assisted her loved one with ADLs, including showering, transfers, driving, medication distribution, cooking, cleaning, and communicating with the health care provider. She reported that her husband has been diagnosed with depression and anxiety. She reported that she lives in a rural region in Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.
- P5 was a female caregiver for her husband who was diagnosed with hearing loss, high blood pressure, and RMD. She was employed at the time of the interview. P5 stated that she assisted her loved one with ADLs, including driving, checking blood sugar levels, medication distribution, cooking, cleaning, and communicating with the health care provider. She reported that her husband has been diagnosed with depression. She reported that she lives in a rural region in Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.
- P6 was a female caregiver for her mother who was diagnosed with macular degeneration, diabetes, dementia, and arthritis/RMD. She was not employed at the time of the interview. P6 stated that she assisted her loved one with ADLs,

including driving, medication distribution, cooking, cleaning, and communicating with the health care provider. She reported that her mother has been diagnosed with depression. She reported that she lives in a rural region in Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.

- P7 was a female caregiver for her husband who was diagnosed with leukemia, diabetes, and chronic pain/RMD. She was not employed at the time of the interview. P7 stated that she assisted her loved one with ADLs, including driving, medication distribution, cooking, cleaning, checking blood sugar levels, transfers, and communicating with the health care provider. She reported that her husband has been diagnosed with depression and anxiety. She reported that she lives in a rural region in Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.
- P8 was a female caregiver for her mother who was diagnosed with foot pain, stroke, and arthritis/RMD. She was employed at the time of the interview. P8 stated that she assisted her loved one with ADLs, including driving, medication distribution, cooking, and communicating with the health care provider when her mother lived with her; however, her mother was currently living with her brother. P8 assists with communicating with the health care provider and managing finances and her mother's property. She reported that her mother has been diagnosed with depression and anxiety. She reported that she lives in a rural region in Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.

- P9 was a female caregiver for her mother who was diagnosed with macular degeneration, diabetes, and arthritis/RMD. She was not employed at the time of the interview. P9 stated that she assisted her loved one with ADLs, including driving, medication distribution, and communicating with the health care provider. She reported that her mother has not been diagnosed with depression, but P9 reported that she felt her mother probably was depressed. She reported that she lives in a rural region in Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.
- P10 was a female caregiver for her mother who was diagnosed with high blood pressure and chronic pain/RMD. She was not employed at the time of the interview. P10 stated that she assisted her loved one with ADLs, including driving and communicating with the health care provider. She reported that her mother has not been diagnosed with depression. She reported that she lives in a rural region in Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.
- P11 was a female caregiver for her husband who was diagnosed with kidney disease, hearing loss, and chronic back pain/RMD. She was not employed at the time of the interview. P11 stated that she assisted her loved one with ADLs, including driving, medication distribution, cooking, cleaning, and communicating with the health care provider. She reported that her husband has not been diagnosed with depression but has exhibited symptoms of depression, stating that he was tired of feeling so badly. She reported that she lives in a rural region in

Texas. She did not tell me her exact age but agreed that she met all inclusion criteria.

- P12 was a female caregiver for her husband who was diagnosed with chronic knee and back pain/RMD. She was employed at the time of the interview. P12 stated that she assisted her loved one with ADLs, including medication distribution, driving, and communicating with the health care provider. She reported that her husband has not been diagnosed with depression but does suffer from severe fatigue. She reported that she lives in a rural region in Oklahoma. She did not tell me her exact age but agreed that she met all inclusion criteria.

Data Collection

I used two methods of choosing a sample, specifically a purposive criterion method and a snowball sampling method to collect data from 12 research participants. Friends, family members, and colleagues posted the recruitment email on social media. I also posted the recruitment email on public bulletin boards in areas where no permission was required to post announcements in various rural communities throughout the Southwestern region of the United States. As a result, 17 potential participants called me and asked for additional information about participating in the research. I answered all their questions regarding participation and 12 agreed to consent to participate and gave me their email addresses.

A recruitment email was sent to each of the 12 potential participants, and I spoke to each on the phone prior to the interview to ask if they had any questions and if they met the inclusion criteria. The interested participants responded that all their questions had been answered and that they self-identified as meeting all inclusion criteria. I emailed the consent form to eleven of the participants and each replied “I consent” in a subsequent email. One participant was given a paper copy of the consent form which she signed. I scheduled a day and time to call them at their convenience. Following the informed consent procedures, I called each participant and asked them the proposed open ended, semi-structured interview questions (see Appendix B). I recorded the interviews with a recording device and transcribed each for analysis. I emailed a copy of the verbatim transcript to each participant and asked them to review it for accuracy. I asked them to inform me of specific inaccuracies in the transcript and I made the required changes to the transcripts. Finally, I verified that the participants were in agreement with the final verbatim transcripts to be used in the data analysis.

I proposed a sample size of ten or to the point of theoretical saturation. Ultimately, I established that theoretical saturation was met with the sample size of 12 as no new information was found in the last four interviews. The interviews ranged in length from 13 minutes to 41 minutes. I hoped that the interviews would be approximately one hour in length, however all questions and probing questions had been asked and answered within the interviews. P10 had the shortest interview length and did not believe that her loved one had any mental health problems or psychological symptoms relative to their chronic pain diagnosis, subsequently having no response to some of the interview questions. Previous researchers have reported relatively short lengths of time of interviews with caregivers as they are attempting to balance thoroughness with respect for the participants demands on their time (McGrath et al., 2019).

After all questions were asked and answered, I thanked participants for their time and openness regarding answering all of my questions. I did not vary from the data collection process in Chapter 3. I did not encounter any unusual circumstances during the data collection process.

Data Analysis

I used the multistep modified van Kaam method for data analysis. After recording each interview, I listened to the audio files four times to immerse myself in the data. I then used web-based technology which is compatible with telephone recordings, Call Recorder, to transcribe each interview. The transcription of each interview was saved to a Microsoft Office Word document. I then edited each transcription for accuracy and sent the verbatim transcription to each participant for verification of accuracy.

After each responded I began the first step of the modified Van Kaam method, specifically horizontalization or looking for common, repetitive text. I printed out each transcription and highlighted all text in each that was relevant to the research question. I then copied and listed each highlighted data segment onto a document specific to that participant reflecting their perceptions of the phenomenon. Secondly, I examined each invariant component regarding indispensability and the likelihood of abstracting and labeling each data segment, otherwise known as the reduction and elimination step of the modified Van Kaam method of analysis. For the next step related to clustering and thematizing the invariant constituents, I copied the data segments into labeled themes regarding their experiences. I then, checked the clustered and labeled data segments against the complete verbatim transcript for each participant regarding explicitness, compatibility, and relevance. Using the remaining invariant constituents and themes, I constructed an individual textural description for each participant. Next, I constructed an individual structural description based on the individual textural description and imaginative variation. Finally, I constructed a textural-structural description of the essence of the experiences including the invariant constituents and themes and subsequently developed a composite description of the meanings of the experience representing the group of 12 participants.

This process resulted in emergent themes regarding the essence of the experiences of the role of caregiver, essence of the experiences of involvement in mental health treatment, and experiences relative to the match between the caregivers' responses and the patients' well-being. Subthemes relative to the essence of the experiences of the role of caregiver include experiences of discomfort in the label of caregiver, relationship between the caregiver and their loved one, and ADLs completed by the caregiver. Subthemes relative to the essence of the experiences of involvement in mental health treatment include accessing treatment specific to types of health care providers utilized, types of mental health treatments utilized, and caregiver perceptions of their efficacy. Subthemes relative to the match between the caregivers' responses and the patients' well-being include supporting patient decision making, advocating for treatment options, and spending time with the patient.

Evidence of Trustworthiness

Trustworthiness is consistent with confidence in the truth of the findings (Constantinou et al., 2017; Silverman, 2017). Qualitative researchers focus on establishing trustworthiness through encouraging credibility, transferability, dependability, and confirmability (Constantinou et al., 2017; Silverman, 2017). I will offer information regarding my attempts to promote each of these in the subsequent sections.

Credibility

Consistent with the information in Chapter 3 of this dissertation, I focused on alignment between the hermeneutical research design, the semi-structured interview questions, and the modified Van Kaam data analysis method consistent with the description in the previous section to encourage credibility. The modified Van Kaam data analysis method was described in the data analysis section of this chapter. I also developed a clear description of the sample's inclusion criteria, specifically regarding rural female caregivers of patients diagnosed with RMD who live in the Southwestern region of the United States to encourage credibility. To promote credibility, I used verbatim transcripts of the interviews to create thick, rich data.

Transferability

Though I described in explicit detail the study processes, transferability of findings will not be generalizable to other populations or contexts. As the sole researcher, I interacted with caregivers of patients diagnosed with RMD creating a text in simply one specific context. Transferability was affected due to the fact that another researcher might elicit different responses than I might be able.

Dependability

I explicitly described the phenomenological research design, methodology, and analysis in specific detail in this chapter to encourage dependability. For this hermeneutical phenomenological study, I sought to promote an accurate description of the shared lived experiences of caregivers of patients diagnosed with RMD to promote dependability. Though I used a protocol for interviews to promote dependability in alignment with hermeneutical phenomenological research which could be replicated by other researchers, my findings will not be replicable because each researcher is a unique individual.

Confirmability

I created verbatim transcripts of the interviews and used member checking to encourage confirmability in the data analysis. I attempted to promote confirmability and to present the meanings that the caregivers of patients diagnosed with RMD offer in the data while simultaneously acknowledging my personal ontology as a caregiver for my husband who has been diagnosed with RMD and as a mental health provider. Also, I shared my potential personal and professional biases to encourage confirmability as mentioned previously in this chapter with the participants throughout the research process.

Ethical Procedures

I was guided throughout this study by Walden University's Institutional Review Board Code of Ethics and the National Association of Social Workers Code of Ethics (National Association of Social Workers, 2017). I offered full disclosure of the nature and purpose of the study in the consent form to the caregivers including answering any questions at any time. I used a consent form to promote the respect for persons by establishing a clear agreement of explicit details regarding what is being asked of them, the potential risks, and potential benefits. I called and encouraged participants to ask questions regarding the research process, consent, or other procedures. To assist in ensuring beneficence, I informed the participants that their involvement in the study is strictly voluntary, and they can withdraw at any time without any explanation. To promote the ethical principle of justice, I attempted to clearly state the rationale for equity in the inclusion criteria I have chosen.

I informed the participants that I would be recording the interview which was saved on an encrypted password protected removable drive. The signed consent forms and interview transcripts were also scanned to the encrypted password protected removable drive. I assigned a code for each caregiver to protect any identifying information and confidentiality. Digital files on the removable drive have been saved in a locked file cabinet in a locked office where I alone have access. I will destroy the data five years after publication in accordance with Walden University guidelines. Additionally, I informed the participants that I will breach confidentially in the event of a disclosure regarding harm to self or others related to child and elder abuse. No disclosure of harm to self or other occurred during any of the interviews.

Results

In the subsequent section, I include the findings of the research project addressing the research question. For this study, the research question asked research participants to describe their experiences of caregiving specific to involvement with their loved ones' mental health treatment. A research question of this complexity and denseness generated core themes and subthemes that are complex and complicated. Through data analysis, I distilled the caregivers' experiences down to three core themes and 11 subthemes that helped me to understand this phenomenon. The components that encompassed the core themes that emerged from each research participant's text included a broad range of concentrations. The three core themes were representative throughout each caregiver's verbatim transcription and the subthemes focus on how each caregiver perceived their understanding and perception of the theme.

First, I include the findings that are labeled and separated into the emergent core theme of the essence of the definition of the role of caregiver and the subthemes related to that of discomfort with the label of caregiver, description of the relationship between caregiver and their loved one, and ADLs completed by caregiver. Secondly, I include the findings regarding the emergent core theme of the essence of the experiences of involvement in their loved one's mental health treatment. Consistent with the description of involvement from Chapter 2 of this dissertation, involvement includes accessing treatment services for their loved one and communicating with their health care providers. I include findings relative to those aforementioned subthemes under specific access to mental health treatment headings of types of health care providers, types of mental health treatments accessed, the caregivers' experiences of treatment efficacy, and discomfort with the label of a diagnosis of a mental health problem. I also include findings under the heading of the subthemes of caregivers' experiences of communications with health care providers. Third, I include findings regarding the emergent core theme related to the match between the caregivers' responses and their loved one's well-being. Consistent with the discussion from Chapter 2 of a patient's well-being including issues of competence, autonomy, and relatedness, I include findings on the subthemes of support for a patient's decision making, advocating for treatment options, and spending time with the patient as a treatment to increase patient well-being.

Core Theme: Essence of the Definition of the Role of Caregiver

The text resulting from the verbatim transcripts revealed a theme regarding the caregivers' meaning of their role as caregiver. The definition for the key concept of caregiver as defined in Chapter 2 of this dissertation referred to a family member who is assisting a patient with their ADLs. Each research participant offered information regarding their experiences as a caregiver in general and some caregivers conveyed their discomfort with the label of caregiver. Specifically, the caregivers offered information regarding three subthemes clarifying the essence of the definition of the caregiving role, specifically their discomfort with the label of caregiver, their relationship to their loved one, and description of the ADLs with which they assist their loved ones.

Subtheme: Discomfort With the Label of Caregiver

The definition used in Chapter 2 of this dissertation was also given to the research participants during the recruitment process prior to their signing the consent form. Five potential participants stated that they do assist their loved ones with their ADLs but still did not consider themselves caregivers and did not want to participate. I thanked them for their time and stated that I completely respect their decision to not participate.

The participants that did agree to sign the consent form in this research study offered a variety of experiences regarding the definition of the term caregiver. Reflecting on the label and definition of the concept of caregiver, nine participants shared that they had previously identified as a caregiver for their loved one in a variety of settings. Three of the 12 participants questioned their identification as caregivers. P10 stated,” I don’t do that much for Mom. Well, she takes care of herself pretty much. I drive her to the grocery store and everywhere she needs to go and that’s it.” She also reports that her mother lives with her but that she is very independent and hardly needs any help at all with ADLs. She stated “when you lose your independence, that’s when you go downhill. As long as she can do for herself, let her go for it.” She stated that she does all the driving for her and assists her when she is sick, including cooking and cleaning. P5 stated that her husband is not an invalid but refuses to do anything for himself. She stated that he looks perfectly normal to the world but “people don’t realize the crap it takes to keep this man going.” P12 stated, “It is just rare that I have to quote unquote take care of him,” but that she daily “is reminding him to take medicine,” and “help him lift and move things around because he can’t.” All three did agree that they meet the inclusion criteria and definition of caregiver used in the dissertation; however, they had not previously thought of themselves as caregivers.

P2 stated that she does identify as a caregiver but feels like she is more of a parent to her husband than a wife. P1 stated that she refers to her caregiving as babysitting. P2 said,

> It's not easy being a caregiver. And you tend to put yourself at the back of the queue, and you almost feel there is a certain responsibility to making sure things are correct. You know that freedom is not there anymore.

Subtheme: Relationship Between the Caregiver and the Loved One

All 12 participants shared information regarding their relationship with their loved one and how that affected their role as a caregiver. Another subtheme of the definition of the role of caregiver is the description of the relationship between the caregiver and their loved one. The research participants were all family members for their loved ones diagnosed with RMD. Four of the 12 participants are caregivers for their mothers and six are caregivers for their husbands. One is a caregiver for her brother, and one is a caregiver for her adult son. Three caregivers gave a great deal of information regarding more than one caregiving experience that they have had. P1 was a caregiver for her mother and her brother. P4 was a caregiver for her husband, her sister, her stepfather, and her mother. P9 was a caregiver for her sister and her mother. Text regarding only one patient was used in the data analysis. The loved one was chosen by the research participant at the time of their review of the verbatim transcript.

Subtheme: ADLs Completed by Caregivers for Their Loved Ones

All 12 participants shared information regarding their loved ones' needs for assistance, how they helped them, and how it affected their role as a caregiver. Specifically, another subtheme of the definition of the role of caregiver includes the types of ADLs with which the caregiver assists the loved one. ADLs that a caregiver might assist their loved one can include but are not limited to transportation, cooking, cleaning, bathing, paying bills, medication distribution, and complex medical care tasks. In this sample of caregivers, ten of the 12 assisted with the driving of their loved one at least part of the time. Eleven of the 12 assisted their loved ones with their medications, primarily reminding them to take them. Nine of the 12 assisted with cooking or preparing meals and eight with cleaning. Complex nursing tasks that caregivers reported completing on at least one occasion include wound care, checking blood sugar levels, catheterization, or checking blood clotting response time. P1 stated that she waited on her loved one hand and foot when he is not doing well. P3 and P8 reported that they assist with their loved ones' financial matters, including managing property, taxes, and insurance.

P7 said,

Draw up his insulin from when he would tell me how much and uh… of course ummm…helping him get dressed uhh to bathe… you know personal things… help him in the bed, sit down on the couch or get up when he had to go to the bathroom and go with him into the bathroom to make sure he didn't fall or anything.

Two caregivers described their loved ones' fear of being alone and that they assisted by physically being around them due to their fear of dying alone. P6 said,

> I think she was afraid she was going to have a stroke, and no one would be there…she couldn't get around because her arthritis was so bad. She couldn't move her hands very well. She couldn't see very well so I think she was just afraid to be alone.

P7 said,

> I think the greatest thing was that he just didn’t want to die alone. So, he felt that he knows he doesn’t have very much time left. And so ummm… that was the thing, that’s why he has somebody come sit with him if I need to go to the store. Mmmmm. And uh … it’s very hard to find yourself restricted to wherever he is in the house. That was very difficult for me.

Core Theme: Essence of the Experience of Involvement in the Patient’s Mental Health Treatment

In the subsequent section, I will offer the findings from the text which emerged as the core theme specific to the research question and the caregiver’s involvement in their loved one’s mental health treatment. Experiences of involvement were defined in Chapter 2 of this dissertation as potentially including accessing the treatment services, communicating with the health care providers, receiving psychosocial support or education services (Lawton et al., 1989; Todorova et al., 2016; Vaughan & Kluger, 2018). The subthemes under access will include findings relative to types of health care providers used, types of mental health treatment used, their experiences of efficacy of the treatment and their experiences of discomfort with the label of the diagnosis of a mental health problem.

Subtheme: Types of Health Care Providers Utilized for the Loved Ones’ Treatment

Caregivers reported that their loved ones had seen a variety of health care providers for treatment of their RMD, including physicians, nurses, physical therapists, social workers, and psychologists. (See Table 1 regarding which health care providers were treating the patient relative to their physical or psychological symptoms of RMD).

Only one caregiver reported that her loved one was referred to a psychologist and seven caregivers reported that their loved one received services from a physical therapist, though only five of those were related to psychological symptoms of RMD. No caregivers reported pain management or psychiatric referrals for their loved ones, though all had diagnoses of chronic pain/RMD.

Table 1

Providers of Mental Health Treatment

Participant	Doctor	Physical therapist	Social worker	Psychologist
P1	*			
P2	*	*	*	
P3	*	*	*	*
P4	*		*	
P5	*			
P6	*	*	*	
P7		*	*	
P8	*	*	*	
P9				
P10				
P11				
P12				

Eight caregivers reported that their loved ones had received services from a social worker even if it was not for mental health treatment. P2, P3, P4, P6, P8, P9 and P11 reported that the social worker kept them informed regarding their loved ones' treatment and was available to answer questions and provide helpful information. P9 said that the social worker is a "bridge between the caregiver and the patient." P7 reported that the social worker provided counseling for the depression and anxiety. P11 stated, "I appreciated her so much" and "she was a very important part of the team in my situation." P1, P5, P10, and P12 reported that their loved one never received any services from a social worker as far as they knew.

Subtheme: Treatments for Mental Health Problems

Numerous treatments are available for the psychological symptoms associated with RMD (Toye et al., 2019). Treatments reported by the research participants in this sample for psychological symptoms of RMD include medications, counseling, physical therapy, meditation, and attending Sr. Citizen Center activities. Seven reported that their loved one was prescribed a medication that the loved one agreed to take, regardless of whether they experienced any positive outcome for their loved one. Two reported that their loved one attended counseling, and one was referred for meditation services. Five reported that their loved ones participated in physical therapy for treatment of both physical and psychological symptoms of RMD, and one attended a Sr. Citizen Center. (See Table 2 showing which caregivers' loved ones were receiving which treatments).

Table 2

Mental Health Treatments Used by Loved Ones

Participant	Medication	Physical Therapy	Counseling	Meditation	Sr. Citizen Center
P1	*				
P2	*	*			
P3	*	*	*	*	
P4	*				
P5	*				
P6	*	*			*
P7		*	*		*
P8	*	*			
P9					
P10					
P11					
P12					

Subtheme: Caregivers' Experiences of Efficacy of Treatment for Their Loved Ones

Researchers of caregivers' perceptions of efficacy of treatment for mental health diagnoses report that caregivers report frustration in getting successful outcomes of treatment for their loved ones' mental health symptoms (Jokogbola et al., 2018; Todorova et al., 2016). Seven of the 12 participants described interventions regarding mental health treatment that they felt positively affected their loved ones. Six of those seven reported that medication had helped reduce psychological symptoms of RMD. P4 stated that her husband would yell and kick their dog, but the physician prescribed a cream that helped him be less violent. P2 stated that she felt the antidepressant helped her husband but that he did not feel like it helped him, so he stopped taking it. She stated that she would make him take it anyway. P5 stated that she did not know if the medication was helping her husband because he would miss many doses for days and knew that must be affecting efficacy. Three of the 12 reported that physical therapy had been a successful treatment for their loved ones' depression. P3 stated that counseling and meditation did not seem to be helpful to her son, but P7 reported that counseling was extremely helpful to her husband. P6 stated that her mother attended a Sr. Citizen's Center which seemed to alleviate some of her mother's depression symptoms.

P8 stated regarding physical therapy,

> Her health improved so rapidly and so dramatically doing that and they were so attentive to her and they would engage her with humor, they weren't patronizing, but they engaged her with humor and umm challenges and that really worked well with her and I

just wish she had more of something like that now to help her umm not just physically but emotionally engaged and overcome where she is right now.

Subtheme: Discomfort With a Label of the Loved One's Diagnosis of Mental Health Problems

RMD refers to a diagnosis of chronic pain and limited functioning which is a progressive disease characterized by associated emotional, social, financial, and societal burden as defined in Chapter 2 of this dissertation (Beggs et al., 2015; Gere et al., 2015; Hemphill et al., 2016). However, all the caregivers in this sample did not report that their loved ones had any mental health diagnosis. Eight of the 12 caregivers reported that their loved ones had been diagnosed with depression or anxiety. Three of those not reporting a mental health diagnosis were P10, P11, and P12, however P10 reported that her mother would get down once in a while, P11 reported that her husband would "get tired of feeling bad," and P12 reported that her husband had extreme fatigue. P9 reported that her mother was not diagnosed with any mental health issues, but she was sure that she had it, but she never saw it. All four of these caregivers reported that no health care provider ever asked their loved ones about depression, anxiety, fatigue, or hopelessness.

P10 stated,

> Her attitude is pretty positive. When she can't do something for herself, she gets upset. She does not like to rely on other people to do things for her." And "She's too busy to be depressed. No…She every once in a while… she'll get down when she can't do something herself, but not too often.

P10 stated, “she doesn’t have doctors that are asking those kinds of things or anything like that. Not while I’ve been with her.”

Subtheme: Caregivers’ Experiences of Communication with Health Care Providers

All 12 caregivers reported communicating with health care providers of their loved ones. Three caregivers reported that the health care providers were supportive and returned their calls in a reasonable amount of time. Ten of the 12 provided the transportation to the appointments, and three of the 12 only reported passively sitting in the appointment. Nine of the 12 caregivers also reported significant participation in their loved ones’ health care treatment, including answering the health care providers’ questions and advocating for changes in the treatment plan. P1 stated, “He didn’t want to tell her everything. And I said Oh No… He’s not gonna tell you then I will tell you.”

P6 stated,

> I always went with her, she asked me to actually because she said she couldn’t remember everything. So anytime she had an appointment I went in the doctor’s office with her and talk to him and uhhhhh made up plans to help her maybe do things a little easier without hurting so much.

P7 said, “It was up to me to keep and carry his paperwork whenever we went to see the doctors, make sure I had all of his paperwork, his list of medicines and that kind of thing.”

Two of the caregivers reported making appointments with health care providers when the loved ones were not present to inform them of the patients lack of compliance or problems with a treatment plan. P5 reported that she has the same doctor that her loved one uses so she made an appointment for herself and only talked about her loved one's noncompliance during the appointment.

P5 reported that the doctor,

> Looked at me and he said that he's not your son. Uh..He is an adult, he's smart, he's a functioning adult, you can't make him. And at that point I walked out of there and to be honest with you and I just sort of forgave myself. Mmmm. And I continue to try. The food is here, and the medicine is where it always is and I encourage him that if he doesn't … if he makes the choice to not take the medicine and eat the food then it's his choice, not mine.

P8 stated that she taught her loved one's physician's child in school and would talk to the physician on the phone regarding the loved one's need for additional treatment or concerns. P8 reported that her loved one benefitted greatly from physical therapy.

Five of the 12 caregivers reported frustrations regarding feelings of being ignored by health care professionals. P2 reported "types of intimidation. At your age, you shouldn't expect to go out and run a marathon. Well, that's not what he wants to do." P11 stated that she noticed a reduction in face-to-face contact from the doctor as her husband became more and more ill. P4 reported frustrations with her husband's doctor not listening to her need for assistance with the patient and the potential for a hospice referral.

Core Theme: Caregivers' Experiences of the Match Between the Caregivers' Responses and the Patients' Well-Being

The research question for this research study focused on shared lived experiences of caregivers of loved ones diagnosed with RMD, specific to their involvement in their mental health treatment. Through data analysis, another core theme emerged from the findings relative to the caregivers' experiences of the match between their responses to their loved ones' mental health needs and well-being. Though all 12 caregivers did not report that their loved one had been diagnosed with a mental illness, all research participants described their experiences assisting their loved one suffering from either fatigue, hopelessness, depression, or anxiety. The match between the caregiver's response and the patient's need can result in increased quality of life for the patient, decreased mental health issues, and increased well-being (Da Silva Barreto et al., 2018; Hemphill et al., 2016; Uysal et al., 2017). As defined in Chapter 2 of this dissertation, the caregivers' responses can be considered solicitous, problematic, or empathic (Beggs et al., 2015; Gere et al., 2015; Hemphill et al., 2016). The responses can directly and indirectly effect the loved ones through increasing autonomy, competence, and feelings of relatedness which are directly related to feelings of well-being (Berry et al., 2017; Dures et al., 2016; Flurey et al., 2017). The subthemes which emerged from the caregivers' texts include support for the loved ones' decision making regarding their treatment, advocating for additional treatment options, and spending time with the patient to decrease mental health symptoms.

Subtheme: Support for Decision Making

Caregivers offered data that was clustered into a subtheme of support for their loved ones' decision making which relates to the caregiver's response to their loved ones' need for autonomy and competence. All 12 caregivers offered information regarding their experiences of supporting their loved ones' decisions to not take medications prescribed (such as flu or Covid vaccine, antidepressants) and not follow the doctor's order (such as quit smoking, following a diabetic diet, discontinue physical therapy or other treatment options). Some caregivers reported excuses for not being upset with noncompliance which included showing signs of respect and love and still others pushed in some areas for their own need for integrity.

Some described experiences that they encouraged the patients in complying with the doctor's orders and then later giving up. P4 reported that her husband was supposed to quit smoking and she would encourage him to stop but over time decided that she would just let him do what he wants to do. P6 reported that her mother was attending a Sr. Citizen Center for activities and lunch.

P6 said,

> She enjoyed it for a while, but then just got tired of getting up and leaving and she just decided she just didn't want to do it anymore. We talked about it, you know, I mean about the repercussions if she turned it down then you have to reapply and all of that. But she was ready to not do that.

P6 said,

> She really disliked taking all that medicine and she took a lot I mean she probably took 20 pills a day. So, it required her to drink a lot of water which then of course kept her up all the time. She would get where she just was not gonna do it. And I would say Mama you have to because if you don't take your medicine, you're gonna feel worse…we would talk about…ever so gradually while we're talking, she would like to take one little pill at a time. Or I would call my husband. She truly loved him and would do anything for him.

P1 stated regarding her loved one's antidepressant medication, "I called him out on it. He said if I ever tell you I feel so good, I'm not gonna take it anymore. That's when you need to say, take your damn medicine."

P5 reported that she felt frustration because her husband will not do anything to help his situation be better and stated,

> From the caregiver's side, that there's a lot of different emotions from that side in the past, it infuriated me, and I wanted to lash out and I wanted to argue the point. I wanted to hit him in the head with a skillet. Uhhhh. I don't care what he says, you know, I'm just numb to it. I just let him say it and I say, ok, walk away. I don't even feel callous about it anymore. At first I did though.

Subtheme: Advocating for Treatment Options

Caregivers also reported advocating for their loved one's medical and mental health treatment options. P1 reported that she "hounded" her brother "relentlessly." She stated, "he was invited by a dermatologist in Dallas to be a part of a double-blind study with arthritis and, ummm, this psoriasis" and "he said, I just really don't have time. And I said, you don't have time not to." After he enrolled in the pharmaceutical trial, P1 stated "now he's on it. And I cannot tell you how much better he feels, he looks, he walks." P1 stated "this infusion every month has changed his life."

P8 reported regarding an oncologist:

> I could talk to him and say here's the deal when she starts getting low on blood or iron or whatever it is …it impacts her tremendously. She gets depressed. She has no energy. I'm afraid she's gonna fall. I work. I need to know that she's okay when I'm not at home. And he devised a health plan where he checked her sometimes monthly when it was…seemed to be going very quickly, you know, south. But typically, it was every 3-6 months depending on the last test and what insurance would do. And he would do preventive care and give her iron infusions in advance. And that was one of the ways I kept her healthy.

To increase positive outcomes from the prescribed treatment, P3, P7, P8, and P12 recommended that caregivers attend at least the first physical therapy sessions with their loved ones to better understand and assist them with treatment. P3 recommended that caregivers read information on the internet about other caregivers' experiences. P3 reported "I think it's hard for people to realize the strains and the stress that the caregivers are under unless they've experienced it themselves."

Subtheme: Spending Time as a Treatment for Mental Health Problems

Caregivers offered data that was clustered into a subtheme of spending time with their loved one. When discussing their loved ones' mental health issues and the essence of their caregiving experience, all 12 reported experiences of “spending time” with their loved one to help them feel better physically and psychologically.

P6 said,

> When she got feeling way down in the dumps at least once a week and sometimes two or three times, I’d say okay we need to do something. Okay we’re gonna go for a drive…Mmmm..I don’t want to go anywhere. I said well you don’t have to, just sit in the car and I always had to end it, it was required, you always had to end it with the McDonald’s ice cream cone.

P9 reported that she would take her loved one to a casino when she noticed that she was feeling down and depressed. P11 reported that she and her loved one never missed church as an opportunity to get out of the house and be around others. P3 and P10 reported that they would invite family members over to socialize with their loved one when they were feeling down. P1 stated that she spent many hours discussing their childhood with her loved one as an opportunity to process the past. “I talk to him even if I don’t feel like it. It doesn’t matter. I just do it because he’s my family.” “I wouldn’t do it for anybody else.” She reported “It’s his therapy.” P6 stated “seeing her happy you know that makes you feel good. Yeah, you don’t want to have her down and depressed and not be able to help her.”

P9 said,

> She would get up at six o’clock every morning and turn on the tv and watch the Mass without fail. She was always watching her Mass. So, if I was there, I was

> gonna watch Mass. Get me some coffee and I'll sit and watch it with her or whatever.

P9 stated, "once you wear out your caregiver, you're kind of in a bad way. Most families will say I can't do this anymore, you know, because they haven't had any assistance for one reason or another." "Maybe they just need an aide to come and help them with the bath and feed him and it's just it's very frustrating. Yes, you know, I didn't need help till I needed help."

Summary

In Chapter 4, I offered the findings from the research, including the purpose of the study, research question, setting, demographics, evidence of trustworthiness, and ethical procedures. The caregivers' transcripts from the interviews resulted in thick, rich text that was used in data analysis resulting in three core themes. One of the themes regarding the essence of the definition of the role of caregiver included the discomfort that some caregivers had about the label of caregiver. Another theme regarding the essence of the experience of involvement in the patient's mental health treatment included the experiences of discomfort that some caregivers had about labels related to a mental health diagnosis. Finally, the theme regarding caregivers' experiences of the match between the caregiver's responses and the patient's well-being included the positive effects on the patient's quality of life when the caregivers spent time with them. In Chapter 5, I will review the interpretation of the findings, limitations of the study, recommendations for future research, and implications regarding social change.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this hermeneutical phenomenological study was to explore the shared lived experiences of female caregivers (ages 65–70) of patients diagnosed with RMD living in the rural Southwestern region of the United States, specific to their involvement with health care providers of mental health treatment of their loved one. To accomplish this, I collected and analyzed data from interviews with 12 caregiver participants. These data included detailed responses to semistructured interview questions created to gather information relative to the research question. Data analysis results were three core themes and 11 subthemes. The core themes were (a) essence of the definition of the role of caregiver, (b) essence of the experience of involvement in the patient's mental health treatment, and (c) experiences of the match between caregivers' responses and patients' well-being; these core themes assist in illuminating the essence of the caregivers' collective experiences.

The majority of the research participants shared their experiences regarding involvement in their loved ones' mental health treatment; however, four participants stated that their loved one did not have a mental health diagnosis. All 12 participants discussed experiences in the role of caregiver and the positive mental health effects their loved one experienced by spending time with them. All the caregivers also offered information regarding their role in advocating for treatment options and in supporting their loved ones' decision making.

To address a gap in the literature regarding these caregiver experiences, I focused on female caregivers’ involvement in accessing information and support from mental health care providers in medical settings. In response to the increasing number of patients diagnosed with RMD requiring assistance with ADLs, these caregivers contribute to the patients’ ability to avoid expensive paid assistance and to stay in a preferred housing environment (Milano, 2017; Morelli et al., 2019; Shugrue et al., 2019). In the next section, I offer interpretations of the results reported in Chapter 4.

Interpretation of Findings

RMD is a complex diagnosis that includes both physical and psychological components (Duenas et al., 2016; Jonas et al., 2019; Toye et al., 2018). The literature has shown that patients’ quality of life improves when caregivers are involved in their treatment (Keast et al., 2020). Health care providers of patients diagnosed with dementia, cancer, and multiple chronic illnesses agree that a patient’s well-being can depend on how their caregiver responds to the patient’s needs (Jonas et al., 2019). Additionally, a gap exists in the empirical research regarding caregivers’ perceptions of being involved in their loved ones’ mental health treatment (Keast et al., 2020).

The research question for this study was focused on caregivers’ perceptions of involvement in their loved ones’ mental health treatment. All caregivers reported that they were involved in medical and mental health treatment of the patients either directly or indirectly. Types of involvement included administering medications, transportation to doctor appointments, scheduling appointments, and assisting with other ADLs such as supporting decision making, spending time with them, and advocating for treatment options. In the next section, I will discuss the interpretation of findings of this study relative to the caregiver's involvement.

Types of Involvement

Patients diagnosed with dementia, cancer, and other chronic illnesses experience psychological and physical challenges in meeting the demands of daily living and may require assistance from a caregiver (Berry et al., 2017; Duenas et al., 2016). Caregivers might assist patients with ADLs related to obtaining treatment services such as transportation to and scheduling of medical appointments (Berry et al., 2017). This study's findings confirm previous literature indicating that caregivers are involved in the health care treatment of their loved ones; every participant caregiver shared that they assist their loved one with ADLs, including transportation to medical care and communication with health care providers.

The majority of caregivers in this study reported that they assist with medication distribution and at least occasionally cooking and cleaning for their loved ones to support compliance with medical recommendations. Only a few participants stated they assist with financial matters for the loved ones such as insurance and other benefits directly affecting a patient's compliance with health care treatment. Research shows that caregivers are being asked to assist loved ones with increasingly complex nursing tasks (Lynch, 2017; Reinhard & Young, 2019; Shugrue et al., 2019; Vaughan & Kluger, 2018). Several caregivers reported assisting with complex nursing tasks, including catheterization, wound care, checking blood pressure, and checking blood sugar levels.

Previous researchers found that the inclusion of caregivers in the treatment planning and implementation for patients could be beneficial, resulting in positive outcomes for loved ones (Duenas et al., 2016; Hansen & Bjerrum, 2016; Hawamdeh et al., 2017; Jokogbola et al., 2018; Lynch, 2017). Caregivers might schedule appointments, attend appointments, and need information from health care providers to effectively assist their loved ones (Da Silva Barreto et al., 2018; Hemphill et al., 2016; Uysal et al., 2017). Previous researchers have also found that caregivers express a desire for health care providers to include them in patients' mental health treatment, specifically through decision making, education, and support (Jokogbola et al., 2018; Nowakowski & Sumerau, 2017; Todorova et al., 2016). A caregiver's confidence in a patient's ability to meet their needs and manage the symptoms of RMD might increase from such information (Da Silva Barreto et al., 2018; Hemphill et al., 2016). The findings in this study confirm this existing knowledge.

All 12 caregivers reported having experiences communicating with health care providers for their loved ones. Most of them were primarily related to transportation and attending appointments with health care providers. The majority reported significant roles in communicating with health care providers, including answering health care providers' questions for the loved one or advocating for changes in the treatment plan. A few participants scheduled appointments with doctors when the loved one was not present to discuss their care and concerns. One participant reported having the same doctor her loved one uses, so she made an appointment for herself and only talked about her husband's noncompliance during the appointment.

Most of the 12 participants reported positive experiences related to health care providers quickly returning their calls and to their love ones' positive feelings toward the health care providers and the care they were receiving. This is consistent with Hansen and Bjerrum's (2016) findings in their systematic review of perceptions of caregivers regarding communication with health care providers. One participant in this study stated that she taught her loved one's physician's child in school and would talk to the physician on the phone regarding the patient's need for additional medication or medical treatment.

Some of the research participants reported occasional experiences of feeling frustrated and ignored by health care providers, including feelings of intimidation and confusion in attempting to advocate for their loved ones and depersonalization from health care providers consistent with findings in previous research (Jokogbola et al., 2018; Todorova et al., 2016). One research participant stated that she noticed a reduction in face-to-face contact from the doctor as her husband became more and more ill. Another research participant reported frustrations with her husband's doctor not listening to her need for assistance with the patient and the potential for a hospice referral.

Supporting Decision Making

All the participant caregivers in this study offered information regarding their responses to the patients' need for support in decision making regarding their medical care. Previous researchers have found that caregivers who are informed by the health care provider of medical information, including potential recommendations and treatment, adjust their support and responses to their loved one regarding assistance (Hemphill et al., 2016; Uysal et al., 2017). Caregiver responses to a patient's needs can be empathetic, problematic, or solicitous (Beggs et al., 2015; Gere et al., 2015; Hemphill et al., 2016). Previous researchers found that a caregiver's response affects a patient's well-being and use of contrary coping strategies (Beggs et al., 2015; Uysal et al., 2017). An empathetic response from a caregiver occurs when a caregiver attempts to match the level of assistance offered with the patient's level of need for support, which increases patient well-being (Gere et al., 2015; Hemphill et al., 2016; Schulz et al., 2017). Well-being is related to the achievement of three basic psychological needs: competence, autonomy, and relatedness (Berry et al., 2017; Dures et al., 2016; Flurey et al., 2017). Research has also shown that a patient's perception of too much or too little help correlates with decreases in perceptions of well-being (Beggs et al., 2015; Duenas et al., 2016; Dures et al., 2016; Uysal et al., 2017).

As defined in Chapter 1, *relatedness* is having a sense of feeling authentically connected to others (Berry et al., 2017; Dures et al., 2016; Flurey et al., 2017). A caregiver responds and is available for support due to concern about a patient's well-being is an aspect of the relationship and accomplishing goals as a team (Helgeson et al., 2018; Todorova et al., 2016). A caregiver attempts to understand a patient's perspective and offers an attitude that the dyad is working together to cope with the chronic pain diagnosis resulting in increased patient well-being (Gere et al., 2015; McGilton et al., 2018; Todorova et al., 2016). The data in this study confirmed previous literature regarding empathetic, solicitous, and problematic caregiver responses. All 12 caregivers reported having experienced times when they advocated for their loved one to not follow the health care providers' orders—specifically, not taking prescribed medications. Some participants discussed their support for the patient’s autonomy by refusing a flu shot, COVID-19 vaccination shot, or antidepressant. Others discussed their support for the patient to continue smoking, not follow a prescribed diet, or stop physical therapy. Some caregivers reported experiences of frustration with the loved one regarding noncompliance at first, but then they chose to respond empathetically and to support their loved one’s need for autonomy and competence, which can increase well-being.

Problematic responses discussed in previous literature include examples of caregivers being angry at the patient for not taking their medication as prescribed or not following a doctor’s orders (Schulz et al., 2017). At other times, caregivers advocated for a patient to follow a doctor’s orders because of the caregiver’s need to feel integrity, which caused them to push their loved one into compliance. Some caregivers were frustrated that their loved one did not do as much for themselves and was not as compliant as they could be. One of the participants expressed a great deal of anger toward the patient due to noncompliant decisions. The participant shared that she felt frustration because her husband would not do anything to help his situation improve; she voiced this frustration as ranging from wanting to hit him in the head with a frying pan to ignoring him and walking away. Another participant reported that her loved one was prescribed medication for anxiety and pain control, but he refused to take it because he was afraid of becoming addicted. These findings support findings in previous literature. However, no information was gathered from loved ones in this study, so whether they perceived these responses of support for decision making as empathetic or problematic remains unknown.

Advocating for Treatment Options

Another component of involvement included in all of the caregiver's interviews was advocating for their loved one's treatment options. Some caregivers were frustrated with the lack of treatment options and others did not even consider that there could be any other treatment options. One participant stated that her loved one was referred to palliative care and was offered meditation but this would require an hour drive from their rural community so they decided not to use those services. Another participant reported that the surgeon first told her that there was nothing they could do to help her loved one but she insisted and then the doctor ordered chemotherapy. The participant questioned if the doctor only did this because he was aggravated with her and wanted to put a band aid on her.

Previous research found that caregivers experiences included feelings of intimidation, frustration, and confusion in attempting to advocate for their loved ones and depersonalization from health care providers (Jokogbola et al., 2018; Todorova et al., 2016). Some findings from this study disconfirmed the findings of previous research. The research participants in this study reported experiences of health care providers listening to them and working with them towards positive treatment outcome options for their loved ones.

One caregiver reported that they advocated for their loved one participating in a medication trial when the loved one was saying they thought they were too busy. Another participant reported that she relentlessly hounded her brother to participate in a study regarding a new medication for RMD and subsequent psychological symptoms when he stated that it was inconvenient. As a result, she said that his quality of life has been changed for the better, both physiologically and psychologically.

A few caregivers called their loved ones' health care providers to discuss the treatment plans without including the patient. One of these worked with the doctor regarding preventative treatment and iron infusions. The participant stated that she discussed a preventative plan for iron infusions for her loved one, specifically a need to do lab work regularly at planned intervals to establish ahead of time the need for an infusion rather than waiting until her loved one showed symptoms of depression, fatigue, and increased risk of falls.

Lack of Use of Specialists Regarding Chronic Pain

As discussed in Chapter 1, health care providers could include physicians, nurses, social workers, psychologists, dieticians, and physical therapists or any professional that uses medical and nonmedical treatments for chronic pain specific to RMD which could include medication, physical therapy, meditation, counseling, diet, and more (Fiest et al., 2017; Lim et al., 2017). When compared to the findings in the literature, this study's findings confirmed the types of health care providers that the loved ones had used in their mental health treatment. Research shows that in rural communities many different types of health care professionals might offer mental health treatment rather than a traditional mental health professional such as a psychologist, psychiatrist, or counselor (American College of Rheumatology, 2015). There is a lack of use and availability of these professionals in rural communities (American College of Rheumatology, 2015). Only one caregiver reported that their loved one had seen a psychologist, and none had received treatment from a psychiatrist. None of the patients were reported to have seen an occupational therapist or pain management clinic, though a majority reported that their loved one received treatment from a physical therapist. A little over half reported that their loved ones received treatment from their physician for their mental health diagnosis which confirms the previously discussed research regarding the need for physicians to have specialized knowledge and training regarding the psychological symptoms of RMD and potential treatment options (American College of Rheumatology, 2015). The majority reported that their loved one had received services from a Social Worker. I did not ask additional questions regarding why the caregivers believed that their loved one was not referred to specialists such as occupational therapists, psychologist, psychiatrists, and counselors. Compared to previous literature, this study's findings confirmed a lack of utilization of these specialized health care providers and a strong reliance on only receiving treatment for a complex chronic pain diagnosis and mental health episodes from primary care physicians (American College of Rheumatology, 2015).

Lack of Awareness of the Complexity of a Chronic Pain Diagnosis

RMD results from a complex interaction between physiological and psychosocial elements resulting in symptoms of pain, anxiety, depression, and fatigue which might be treated separately or concurrently (Duenas et al., 2016; Jonas et al., 2019; Toye et al., 2018). Treatments might be medically focused by prescribing medications or nonmedically by referring a patient to a mental health provider, or both (Dures et al., 2016; Jonas et al., 2019). No caregiver reported that any health care provider had ever discussed the complexity of their loved one's diagnosis with them, specifically related to the knowledge base regarding chronic pain and the likelihood of mental health complications.

Two thirds of the participants stated that their loved one had a diagnosis of a mental health problem but did not directly or indirectly correlate it with the RMD diagnosis. One third of the participants stated that the health care providers never asked their loved ones about any mental health symptoms. One participant seemed uncomfortable with the possibility that her loved one was suffering from any mental health problems, such as depression, fatigue, hopelessness, or anxiety. She reported that her mother was too busy to get depressed but that she would get down once in a while when she felt dependent on others. She denied that any health care providers had asked her loved one any questions about mental health problems.

A few of the caregivers reported that their loved one had symptoms of being down, fatigue, and hopelessness, but denied that their loved one had a mental health diagnosis or needed treatment. If a mental health provider in a medical setting does not screen a patient for potential psychological symptoms and offers only general physiological information to caregivers regarding a diagnosis then the perpetuation of mental health stigma might result (Cagle & Bunting, 2017; Da Silva Barreto et al., 2018; Dures et al., 2016). With better assessments, caregivers might be more likely to respond empathically to patients and better assist in managing the symptoms of the diagnosis (Da Silva Barreto et al., 2018; Hemphill et al., 2016). Consequently, the findings of this research extends the existing knowledge base relative to experiences of discomfort by a caregiver. The specific causes of the caregivers' discomfort is unknown as I did not ask additional questions regarding this.

The majority of caregivers offered information regarding type of treatment offered to their loved one and its efficacy in improving well-being. Though only two thirds of participants agreed that their loved one had a mental health diagnosis, all discussed mental health symptoms that their loved ones suffered. Previous literature discussed interventions including educationally based treatment programs involving case management services, nutrition services, occupational therapy, psychiatric services, and pain management services, no caregiver reported that their loved one was referred to those types of programs (Berry et al., 2017; Dures et al., 2016; Jonas et al., 2019).

Efficacy of Treatment

Physicians report frustration regarding the empirical evidence for successful treatment options regardless of the biopsychological focus of the treatment (Schatman, 2015). Numerous researchers recommend including the caregiver in the patients' treatment and asking them for feedback regarding efficacy of the treatment (Duenas et al., 2016; Hansen & Bjerrum, 2016; Hawamdeh et al., 2017; Jokogbola et al., 2018; Lynch, 2017). Caregivers are around the patients regularly and notice changes in the patient's physical and psychological symptoms (MacLeod et al., 2021). Previous researchers have explored this topic asking caregivers if they felt that patients diagnosed with HIV, dementia, and other chronic illnesses had positive or negative outcomes from specific treatments. They found a lack of consensus regarding which treatments were more effective at increasing well-being (Bipeta et al., 2020). The findings from this study seems to extend the existing knowledge base regarding caregivers in rural Southwestern region of the United States and caregivers of patients diagnosed with RMD. The majority of caregivers reported that their loved one was prescribed medication to treat psychological symptoms of RMD, some of them said the medication seemed to decrease their loved one's mental health problems.

Spending Time

All 12 caregivers reported that there were positive outcomes for their loved ones both psychologically and physically when they spent time with their loved one. Some reported that they enjoyed it and others reported that they resented it. This is connected to an empathic response and relatedness. Creating a feeling of working together as a team takes time, so it makes sense for the caregiver to spend time with the patient for them to feel relatedness. Patients need time to process what help they need, time to figure out if they can do an activity on their own, time to communicate, or experience so they can receive the help (Crowe et al., 2017). Some caregivers reported experiences of frustration and then choose to slow down creating an empathic response.

Every caregiver in this study reported that they experienced increases in their loved one's well-being and decreased mental health symptom when they spent time with their loved one. The findings from this study extended the previous knowledge base. One such experience was reported by a participant in that she would take her loved one for a ride in the car when she seemed to be feeling down. She stated that her loved one would object at first but with coaxing she would eventually agree and enjoyed an ice cream cone at the end of their ride. Some of the research participants reported specific activities that they would do with their loved one, like go to the casino, church, and invite other family members over to socialize. Another added her experience regarding quality time and that she spent many hours discussing their childhood with her brother as an opportunity to process the past. She discussed that she talked to him even when she did not want to because she felt obligated to him as a family member and that it was part of his therapy which improved his quality of life.

Research regarding patient's perspectives of the need for professional and nonprofessional caregivers to assist as quickly or slowly as the patient wanted greatly resulted in positive outcomes for the patient (Berry et al., 2017). Some caregivers experienced their loved ones being upset because they did not get the assistance they wanted as quickly as they wanted it. Other caregivers experienced situations where the loved one asked them to slow down and give them time to process and respond to the help. Slowing down or responding quickly can also relate to the patients' need for autonomy and competence (Berry et al., 2017).

The caregivers offered experiences of the patient wanting to accomplish certain tasks by themselves so the caregiver had to give them time to do it their own way and at their own pace. Previous researchers reported that patients have expressed feelings of hopelessness when the caregiver was too quick to solve the problem instead of believing that they were capable of solving it (McGilton et al., 2018). Some caregivers reported that spending time also decreased their loved one's fear of loneliness and isolation, and specifically fear of dying alone.

Discomfort With the Label of Caregiver

The inclusion criteria for this study required that all participants self-identify as a caregiver. The definition of caregiver used in this study was broad which could have resulted in limitations in the findings. Of the 17 respondents who initially reached out to me regarding participating in the research project, five of them expressed discomfort in labeling themselves as caregivers even after given the definition used in Chapter 1. Four of the 12 that consented to participate stated that they had not considered themselves caregivers prior to speaking with me however they did agree that they met the definition of caregiver used in Chapter 1. Some of the research participants in this study described their experience as stressful and hard while others insisted that they didn't hardly do anything for their loved one, minimizing their assistance and then continue to explain that there are many ways that they are involved in the health care treatment for their loved one.

As discussed in Chapter 1, patients diagnosed with cancer, dementia and other chronic illnesses often experienced psychological and physical challenges in accomplishing the requirements of daily living and need assistance from a caregiver (Duenas et al., 2016). These difficulties faced by the patient also affect the caregiver (Berry et al., 2017; Duenas et al., 2016). The findings of this study extend the knowledge base regarding experiences of caregivers of patients diagnosed with dementia by examining caregivers of patients diagnosed with RMD. The previous studies' findings included issues related to caregiver burden and caregiver stigma (Jokogbola et al., 2018; Todorova et al., 2016). Caregiver stigma was defined as negative perceptions of characteristics of caregivers as individuals (Zwar et al., 2021). Previous research has found that as caregiver stigma increases so does caregiver burden. This additionally tended to decrease the likelihood of a caregiver in asking for help (Zwar et al., 2021). It is possible that the research participants in this study also experienced caregiver stigma and that was why they reported some discomfort in the label of caregiver. This is unknown as additional questions were not asked regarding caregiver stigma or perceptions of the caregiver's label.

Limitations of the Study

The evidence provided in this hermeneutical phenomenological research design does not support transferability or the applicability of the findings to other contexts (Moustakas, 1994). I collected data through interviewing 12 women who are caregivers for loved ones diagnosed with chronic pain and had experienced mental health episodes with loved ones, and subsequently, this data may not be directly applicable to men, other caretakers, or other women. I interviewed 12 women who lived in the rural Southwestern region of the United States which hinders the transferability to urban dwelling caregivers or those living in the Northeastern region of the United States. My research process was reliant on participants sharing information to form a text which could include challenges of unknown biases, problems of recall, and misunderstanding regarding the asked question (Moustakas, 1994).

The process of data gathering for a qualitative study requires self-reports from caregivers, and this may yield information that is unintentionally biased, intentionally biased, or influenced by social desirability (Hefti & Bussing, 2018; Oxhandler &

Pargament, 2018). The assumption was made that these participants openly and willingly shared their experiences as engaged participants in the research process discussing their experiences with caregiving and involvement in mental health treatment of their loved ones. My sample size of 12 caregivers might have excluded additional participants whose shared lived experiences had not been captured in the data. Differences in culture, context, and other variables of the participants might not be accurately considered resulting in an exaggeration or denial of information regarding the lived experiences of caregivers (Pryma, 2017).

As a phenomenological exploration of the lived experiences of caregivers involved in mental health treatment, I wanted to advance my understanding of how caregivers perceived the phenomenon. Initially, when I proposed this study and considered the potential participants who might have responded, I assumed that most of the respondents would be comfortable with the label of caregiver. However, I was surprised that one third of the participants were concerned that caregiver was an appropriate label for them even though they were assisting their loved ones with their ADLs.

The inclusion criteria used to acquire the sample of participants for this research study was to be female and between the ages of 65 and 70, therefore, the data generated from this study cannot be generalized across all caregivers in the United States. The transferability of this study is supported by data that contains thick descriptions of the participants' experiences; however, it should be mentioned that the rich, in-depth, and textured data, narrative, descriptions, and quotations provided by these participants of their experiences with caregiving might be considered by some caregivers as inaccurate and not reflecting their experiences in urban areas or other parts of the US.

Because this research study was conducted during a worldwide pandemic, it is not possible to clarify what limitations may have been caused by it. Participants were interviewed over the phone, which may have affected or influenced their responses or their participation. Every participant was sent a complete copy of their transcribed interview to review for accuracy, however, two participants elected not to edit theirs, preferring to rely on the skill and accuracy of the transcriber. Though I checked each transcription against each audiotaped interview to verify its accuracy before sending it out to participants, I still missed several minor errors that were corrected. Ten participants reviewed their transcripts and offered feedback regarding accuracy to correct any mistakes I had made.

Another potential limitation might have resulted from my inexperience as a qualitative researcher and as an individual who has a collection of inextricable biases. This was my first experience interviewing participants as part of a hermeneutical phenomenological research study. Because of the generosity of time and accessibility that the participants showed, I must admit that I felt intimidated at times. Therefore, any actual or perceived deficiencies in the content of the verbatim transcripts from the participants may be due to my inexperience as a qualitative interviewer. In every interview, the participants were gracious, patient, and encouraging. I genuinely hope that all facets of my data collection, analysis, and presentation of their lived experiences in this research are respectful of my participants' selfless contribution to expanding the understanding of the complex phenomena of caregiving by sharing their stories with me.

Recommendations

I will discuss recommendations regarding training, research, and policy in the subsequent section. Training and research are interrelated in that professionals look to the empirical evidence in research to create training curriculum (Fautrel et al., 2018). Policies and training are also interrelated in that policies affect what training is required by which professionals (Fautrel et al., 2018).

Training

The data analyzed from this study has provided an increased understanding into how these caregivers experienced the phenomena being explored, thereby increasing understanding of how gaps in the knowledge base among health care providers of mental health treatment may be improved as opportunities for actively acquiring the training and skills recommended to encourage caregiver involvement in mental health treatment of their loved one, but there is much that remains unknown. The consensus among existing research has concurred that current health care treatment practices for patients diagnosed with RMD do not adequately meet the needs of the psychosocial aspects of the diagnosis and the involvement of caregivers (American College of Rheumatology, 2015). Results from this research confirm the need for training for caregivers regarding diagnosis of RMD and how to assist with ADLs including mental health symptoms. Findings from this research may include information that is constructive to training medical social workers in advocating for improvement of interactions with the caregivers and fill a gap in the literature (Reynaert et al., 2019).

Research

As the proportion of older adults increases in the United States, researchers report a compelling need to better understand the issues related to this population including caregiving (Dev et al., 2020). These issues might include a need for assistance with ADLs and an increased need for family caregivers to provide this assistance (Andrews et al., 2017; Otero et al.,2019). With a better understanding of the increasing role of caregivers, practitioners may also increase their understanding in better supports for the caregivers (Andrews et al., 2017; Otero et al.,2019). Recommendations for further research include considering this underexplored topic through additional qualitative research that would allow caregivers across a broader continuum of experience to share the scope and depth of their experiences with involvement in their loved ones' mental health treatment. Additional qualitative research could potentially offer more insights into how caregivers perceive their experiences with these phenomena, whether as negative barriers or as positive opportunities for enrichment, or maybe as something else. Finally, quantitative research is recommended to increase the knowledge base regarding caregivers of patients diagnosed with RMD specifically examining caregiving and mental health stigma.

Policies

Results from this research confirm the need for policies to train healthcare providers to screen patients with chronic pain regarding mental health issues. Policy makers might use these findings to address the need for a reduction of indirect, nonmedical expenses as the number of patients diagnosed with chronic pain increases along with their reliance on caregivers (Chari et al., 2015; Shugrue et al., 2019). The results from this research study indicates a need for policies to encourage more psychiatrists to come to rural areas and other mental health professionals with a specialized knowledge base of chronic pain and its bio psychosocial aspects.

Implications

My hope is that as well as addressing the gap in research in this area in rural communities this study will encourage other researchers in the mental health professions to take a focused and in-depth look at the current limitations and disparities in the knowledge base of support, advocacy, and screening of mental health diagnosis concerning these phenomena. However, it is impossible to predict whether any positive social change will result from this research. I would hope that this research will encourage more researchers to examine both qualitatively and quantitatively the potential role that deficits in training may have on a health care provider’s ability to educate individuals regarding the definition of the caregiver role, advocating for treatment options, education regarding stigma related to mental health diagnosis, and a broader understanding of the complex assessment and treatment of the multifaceted diagnosis of RMD.

The potential to positively impact individuals, groups, and society by generating a more complete and focused understanding of how to effectively and ethically meet the psychosocial needs of caregivers who appear to be uncomfortable with diagnosis and treatment of mental health issues related to chronic pain could result in positive social change. With a more accurate understanding of the experiences of caregivers, the likelihood of positive social change will increase at the individual micro level, the intergroup mezzo level, and the system-wide macro level. Social workers and other health care providers may learn more about whether these perceptions are experienced as a problem to a greater variety of caregivers with more diverse backgrounds.

Additional insights of understanding through continued research into these gaps may offer health care providers an increased opportunity for discovering more potential support for achieving advocacy for their clients who are caregivers. Providing health care providers with a more extensive understanding of the challenges that might occur when interacting with caregivers of patients diagnosed with RMD may assist clinicians in assisting others in an ethically informed and efficacious manner, suggesting that the potential for positive social change might occur anywhere across multiple situations with broader implications.

Conclusion

Caregivers are an important part of their loved one’s lives (Keast et al., 2020). Information to best know how to support this dyad and increase patient well-being is crucial (MacLeod et al., 2021). A careful review of existing literature revealed a consensus among researchers that deficits in involvement of caregivers in the mental health treatment of patients diagnosed with RMD currently exist (Bipeta et al., 2020). The findings from this study have extended the knowledge base regarding caregivers of loved ones diagnosed with RMD.

The purpose of this phenomenological study was to gain additional insight into how caregivers described their experiences with involvement in their loved ones' mental health treatment. While caregivers' numbers are growing, only a handful of studies have explored the gaps and their effects that may occur when so little is known (MacLeod et al., 2021). Therefore, the data generated from this study increased the understanding of the essence of these caregivers' experiences and perspectives on the impact of their involvement in mental health treatment, and how they were able to mitigate those perceived challenges. Although these caregivers' experiences are not representative of the experiences of all caregivers who might be assisting a loved one diagnosed with RMD, their insights highlight a need for greater understanding of the complex diagnosis of chronic pain and caregiving.

References

Al-Fadl, E. M., Ismail, M. A., Thabit, M., & El-Serogy, Y. (2014). Assessment of health-related quality of life, anxiety and depression in patients with early rheumatoid arthritis. *The Egyptian Rheumatologist*, *36*(2), 51–56. https://doi.org/10.1016/j.ejr.2013.12.004

American College of Rheumatology. (2015). *Workforce study of rheumatology specialists in the United States.* https://www.rheumatology.org/Learning-Center/Statistics/Workforce-Study

Andrews, J. S., Trupin, L., Yelin, E. H., Hough, C. L., Covinsky, K. E., & Katz, P. P. (2017). Frailty and reduced physical function go hand in hand in adults with rheumatoid arthritis: A US observational cohort study. *Clinical Rheumatology*, *36*(5), 1031–1039. https://doi.org/10.1007/s10067-017-3541-9

Bacon, I., McKay, E., Reynolds, F., McIntyre, A. (2020). The livened experience of codependency: An interpretative phenomenological analysis. *International Journal of Mental Health and Addiction, 18*, 754–771. https://doi.org/10.1007/s11469-018-9983-8

Balintona, M. L. (2018). *"It gets easier, not better": Ambiguous loss and resiliency in adult children caring for their parent with Alzheimer's disease* [Doctoral dissertation, University of Pennsylvania]. Scholarly Commons. https://repository.upenn.edu/edissertations_sp2/104

Baumbauer, K. M., Young, E. E., Starkweather, A. R., Guite, J. W., Russell, B. S., & Manworren, R. C. B. (2016). Managing chronic pain in special populations with emphasis on pediatric, geriatric, and drug abuser populations. *Medical Clinics of North America, 100*(1), 183–197. https://doi.org/10.1016/j.mcna.2015.08.013

Beggs, R. T., Holtzman, S., & DeLongis, A. (2015). Predicting daily satisfaction with spouse responses among people with rheumatoid arthritis. *Annals of Behavioral Medicine, 50*(1), 24–33. https://doi.org/10.1007/s12160-015-9728-x

Berry, E., Davies, M., & Dempster, M. (2017). Exploring the effectiveness of couples interventions for adults living with a chronic physical illness: A systematic review. *Patient Education and Counseling, 100*, 1287–1303. http://dx.doi.org/10.1016/j.pec.2017.02.015

Betini, R. S. d., Hirdes, J. P., Lero, D. S., Cadell, S., Poss, J., & Heckman, G. (2017). A longitudinal study looking at and beyond care recipient health as a predictor of long term care home admission. *BMC Health Services Research, 17*, 709. https://doi.org/10.1186/s12913-017-2671-8

Bipeta, R., Yerramilli, S. S. R. R., & Pillutla, S. V. (2020). Perceived stigma in remitted psychiatric patients with their caregivers and its association with self-esteem, quality of life, and caregiver depression. *East Asian Archives of Psychiatry, 30*, 101–107. https://doi.org/10.12809/eaap1943

Boehmer, K., Egginton, J., Branda, M., Kryworuchko, J., Bodde, A., Montori, V., & LeBlanc, A. (2014). Missed opportunity? Caregiver participation in the clinical encounter. A video analysis. *Patient Education and Counseling, 96*(3), 302–307. http://dx.doi.org/10.1016/j.pec.2014.05.016

Bom, J., Bakx, P., Schut, F., & Doorslaer, E. (2019). The impact of informal caregiving for older adults on the health of various types of caregivers: A systematic review. *The Gerontologist 59*(5), 629–642. https://doi.org/10.1093/geront/gny137

Brenna, E., & DiNovi, C. (2015). Is caring for older parents detrimental to women's mental health? The role of the European North-South gradient. *Review of Economics of the Household, 14*(4), 745–778. https://doi.org/10.1007/s11150-0159296-7

Cagle, J., & Bunting, M. (2017). Patient reluctance to discuss pain: Understanding stoicism, stigma, and other contributing factors. *Journal of Social Work in End-of -Life & Palliative Care, 13*(1), 27–43. https://doi.org/10.1080/15524256.2017.1282917

Castillo-Montoya, M. (2016). Preparing for interview research: The interview protocol refinement framework. *Qualitative Report*, *21*(5). https://doi.org/10.46743/2160-3715/2016.2337

Chari, A. V., Engberg, J., Ray, K. N., & Mehrotra, A. (2015). The opportunity costs of informal elder-care in the United States: New estimates from the American time use survey. *Health Services Research, 50*(3), 871–882. https://doi.org/10.1111/1475-6773.12238

Constantinou, C. S., Georgiou, M., & Perdikogianni, M. (2017). A comparative method for themes saturation (CoMeTS) in qualitative interviews. *Qualitative Research*, *17*(5), 571–588. https://doi.org/10.1177/1468794116686650

Corvin, J., Chan, I., Tezak, A., Carpenter, K., Aguado Loi, C., Gonzales, J., & Hoare, I. (2017). Caring for individuals with chronic illness and minor depression: Latino perceptions of caregiver burden. *Journal of Gerontological Social Work*, *60*(1), 79–95. https://doi.org/10.1080/01634372.2016.1268230

Crespo, M., & Fernandez-Lansac, V. (2014). Factors associated with anger and anger expression in caregivers of elderly relatives. *Aging and Mental Health, 18*(4), 454-462. https://dx.doi.org/10.1080/13607863.2013.856857

Crowe, M., Gillon, D., Jordan, J., & McCall, C. (2017). Older peoples' strategies for coping with chronic non-malignant pain: A qualitative meta-synthesis. *International Journal of Nursing Studies, 68*, 40-50. https://dx.doi.org/10.1016/j.ijnurstu.2016.12.009

Dahlberg, K. (2006). The essence of essences – the search for meaning structures in phenomenological analysis of lifeworld phenomena. *International Journal of Qualitative Studies on Health & Well-Being, 1*(1), 11–19. https://doi-org/10.3402/qhw.v1i1.4904

Da Silva Barreto, M., Garcia-Vivar, C., & Marcon, S. (2018). Methodological quality of Grounded Theory research with families living with chronic illness. *International Journal of Africa Nursing Sciences, 8*, 14-22. https://doi.org/10.1016/j.ijans.2018.10.001

Denzin, N., & Lincoln, Y. (1994). *Handbook of Qualitative Research.* Sage Publications.

Dev, R., Zaslavsky, O., Cochrane, B., Eagen, T., & Woods, N. (2020). Healthy aging through the lens of community-based practitioners: A focus group study. *BMC Geriatrics, 20,* 1-10. https://doi.org/10.1186/s12877-020-01611-x

DiNovi, C., Jacobs, R., & Migheli, M., (2015). The quality of life of female informal caregivers: From Scandinavia to the Mediterranean Sea. *European Journal of Population, 31* (3), 309-333. Doi: 10.1007/s10680-014-9336-7

Duenas, M., Ojeda, B., Salazar, A., Mico, J., & Failde, I. (2016). A review of chronic pain impact on patients, their social environment and the health care system. *Journal of Pain Research*, *9*, 457-467. https://dx.doi.org/10.2147/jPR.S105892

Dures, E., Fraser, I., Almeida, C., Peterson, A., Caesley, J., Pollock, J., Ambler, N., Morris, M., & Hewlett, S. (2016). Patients' perspectives on the psychological impact of inflammatory arthritis and meeting the associated support needs: Open-ended responses in a multi-centre survey. *Musculoskeletal Care, 15*, 175-185. https://Doi 10.1002/msc.1159

Edwards, C. (2019). Breaking away from the theoretical: von Herrman on Husserl and Heidegger. *The Journal of the British Society for Phenomenology, 50*(2), 139-153. https://doi.org/10.1080/00071773.2018.1526784

Englbrecht, M., Alten, R., Aringer, M., Baerwald, C., Burkhardt, H., Eby, N., Fleidner, G., Gauger, B., Henkemeier, U., Hofmann, M., Kleinert, S., Kneitz, C., Krueger, K., Polh, C., Roske, A., Schett, G., Schmanlzing, M., Tausche, A., Tony, H., & Wendler, J. (2017). Validation of standardized questionnaires evaluating symptoms of depression in rheumatoid arthritis patients: Approaches to screening for a frequent yet underrated challenge. *Arthritis Care and Research, 69*(1), 58-66. https://Doi 10.1002/acr/23002

Fautrel, B., Alten, R., Kirkham, B., Torre, I., Durand, F., Barry, J., Holzkaemper, T., Fakhouri, W., & Taylor, P. (2018). Call for action: How to improve use of patient-reported outcomes to guide clinical decision making in rheumatoid arthritis. *Rheumatology International, 38*, 935-947. https://doi.org/10.1007/s00296-018-4005-5

Fiest, K., Hitchon, C., Bernstein, C., Peschken, C., Walker, J., Graff, L., Zarychanski, R., Abou-Setta, A., Patten, S., Sareen, J., Bolton, J., & Marrie, R. A. (2017). Systematic review and meta-analysis of interventions for depression and anxiety in persons with rheumatoid arthritis. *Journal of Clinical Rheumatology*, *23*(8), 425. DOI: 10.1097/RHU.0000000000000489

Flurey, C., Hewlett, S., Rodham, K., White, A., Noddings, R., & Kirwan, J. (2017). “You obviously just have to put on a brave face”: A qualitative study of the experiences and coping styles of men with rheumatoid arthritis. *Arthritis Care and Research, 69*(3), 330-337. doi10.1002/acr.22951

Fry, J., Scammell, J., & Barker, S. (2017). Drowning in muddied waters or swimming downstream?: A critical analysis of literature reviewing in a phenomenological study through an exploration of the lifeworld, reflexivity and role of the researcher. *Indo – Pacific Journal of Phenomenology, 17*(1), 1-12. http://dx.doi.org./10.1080/20797222.2017.1293355

Fuller, S. (2000). Thomas Kuhn: A Philosophical History for Our Times. University of Chicago Press.

Gadamer, H. (1996). *Truth and Method* (J. Weinsheimer & D. Marshall, Trans.) (2nd Rev. ed.). Continnum.

Gamarel, K., & Revenson, T. (2015). Dyadic adaptation to chronic illness: The importance of considering context in understanding couples' resilience. In *Couple Resilience* (pp. 83-105). Springer, Dordrecht.

Gere, J., Martire, L., Keefe, F., Stephens, M., & Schulz, R. (2014). Spouse confidence in self-efficacy for arthritis management predicts improved patient health. *Annals of Behavioral Medicine, 48*(3), 337-346. Doi:10.1007/s12160-014-9608-9

Giorgi, A. (2006). Difficulties encountered in the application of the phenomenological method in the social sciences. *Análise Psicológica*, *24*(3), 353-361.

Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory*. 1967. Weidenfield & Nicolson.

Guba, E., & Lincoln, Y. (1990). Can there be a human science. *Person Centered Review, 5*(2), 130-154.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods, 18*(1), 59-82. Doi:10.1177/1525822X05279903

Hadi,M., Alldred, D., Briggs, M., Marczewski, K. & Closs, S. (2017). 'Treated as a number, not treated as a person: A qualitative exploration of the perceived barriers to effective pain management of patients with chronic pain. *BMJ Open,* 1-7. Doi: 10.1136/bmjopen-2017-016545

Hagaman, A. K., & Wutich, A. (2017). How Many Interviews Are Enough to Identify Metathemes in Multisited and Cross-Cultural Research? Another Perspective on Guest, Bunce, and Johnson's (2006) Landmark Study. *Field Methods*, *29*(1), 23–41. http://dx.doi.org/10.1177/1525822X16640447

Hansen, C., & Bjerrum, M. (2016). Perceptions of patients, significant others and health professionals of the role of significant others in programs for chronic non-malignant pain patients: A systematic review protocol. *JBI Database of Systematic Reviews & Implementation Reports, 14*(11), 43–49. https://doi-org/10.11124/JBISRIR-2016-003192

Hawamdeh, S., Almari, A., Almutairi, A., & Dator, W. (2017). Determinants and prevalence of depression in patients with chronic renal disease, and their caregivers. *International Journal of Nephrology and Renovascular Disease, 10*, 183-189.

Hearn, J., Cotter, I., & Finlay, K. (2019). Efficacy of internet-delivered mindfulness for improving depression in caregivers of people with spinal cord injuries and chronic neuropathic pain: A randomized controlled feasibility trial. *Archives of Physical Medicine and Rehabilitation, 100*, 17-25. https://doi.org/10.1016/j.apmr.2018.08.182

Heckathorn, D. D., & Cameron, C. J. (2017). Network sampling: From snowball and multiplicity to respondent-driven sampling. *Annual Review of Sociology*, *43*, 101-119.

Hefti, R., & Büssing, A. (Eds.). (2018). *Integrating religion and spirituality into clinical practice*. MDPI-Multidisciplinary Digital Publishing Institute.

Heidegger, M. (1927). *Being and Time.* Translated by John Macquarrie and Edward Robinson. First English Edition.

Heijde, D., Daikh, D. I., Betteridge, N., Burmester, G. R., Hassett, A. L., Matteson, E., Vollenhoven, R, & Lakhanpal, S. (2018). Common language description of the term rheumatic and musculoskeletal diseases (RMDs) for use in communication with the lay public, healthcare providers and other stakeholders endorsed by the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR). *Annals of the Rheumatic Diseases*, annrheumdis-2017.

Helgeson, V., Jakubiak, B., Van Vleet, M. & Zajdel, M. (2018). Communal coping and adjustment to chronic illness: Theory update and evidence. *Personality and Social Psychological Review, 22*(2), 170-195.

Hemphill, R., Martire, L., Polenick, C., & Stephens, M. (2016). Spouse confidence and physical function among adults with osteoarthritis: The mediating role of spouse responses to pain. *Health Psychology, 35*(10), 1059. http://dx.doi.org/10.1037/hea0000383

Herber, O., & Barroso, J. (2019). Lessons learned from applying Sandelowski and Barroso's approach for synthesizing qualitative research. *Qualitative Research,* 1-18. https://doi: 10.1177/1468794119862440

Husserl, E. (1931). *Ideas Toward a Pure Phenomenology and a Phenomenological Philosophy*. Trans. WRB Gibson. Humanities Press.(Original work published 1913).

Jafarzadeh, S. R., & Felson, D. T. (2018). Updated estimates suggest a much higher prevalence of arthritis in United States adults than previous ones. *Arthritis & Rheumatology*, *70*(2), 185-192.

Jokogbola, O. R., Solomon, C., & Wilson, S. L. (2018). Family as caregiver:

Understanding dementia and family relationship. *Advances in Clinical and Translational Research, 2*(2), 100007.

Jonas, W., Crawford, C., Colloca, L., Kriston, L., Linde, K., Moseley, B., & Meissner, K. (2019). Are invasive procedures effective for chronic pain? A systematic review. *Pain Medicine, 20*(7), 1281-1291. Doi: 10.1093/pm/pny154

Jowsey, T., Strazdins, L., & Yen, L. (2016). Worry and time: The unseen costs of informal care. *Chronic Illness, 12*(4)*,* 249-260. doi:10.1177/1742395316647788

Junghaenel, D., Schneider, S. & Broderick, J. (2017). Partners' overestimation of patients' pain severity: Relationships with partners' interpersonal responses. *Pain Medicine, 18*(9), 1625-1651.

Katz, P., Margaretten, M., Trupin, L., Schmajuk, G., Yazdany, J., & Yelin, E. (2016). Role of sleep disturbance, depression, obesity, and physical inactivity in fatigue in rheumatoid arthritis. *Arthritis Care & Research, 68*(1), 81-90. https://doi 10.1002/acr.22577

Keast, R., Butow, P., Juraskova, I., & Laidsaar-Powell, R. (2020). Online resources for family caregivers of cognitively competent patients: A review of user-driven reputable health website content on caregiver communication with health professionals. *Patient Education and Counseling, 103*, 2408-2419. https://doi.org/10.1016/j.pec.2020.04.026

Kleinman, A. (2015). Care: In search of a health agenda. *Lancet*, *386*(9990), 240–241. https://doi.org/10.1016/S0140-6736(15)61271-5

Kindt, S., Vansteenkiste, M., Loeys, T., Cano, A., Lauwerier, E., Verhofstadt, L., &

Goubert, L. (2015). When is helping your partner with chronic pain a burden? The relation between helping motivation and personal and relational functioning. *Pain Medicine, 16*(9), 1732-1744.

Koster, E., Hoorelbeke, K., Onraedt, T., Owens, M., & Derakshan, N. (2017). Cognitive control interventions for depression: A systematic review of findings from training studies. *Clinical Psychology Reviews, 53*, 79-92. http://dx.doi.org/10.1016/j.cpr.2017.02.002

Kuhn, T. S. (1962). *The Structure of Scientific Revolutions*. The University of Chicago Press.

Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology*, *44*(3), P61-P71.

Lee, J., & Spratling, R. (2019). Recruiting mothers of children with developmental disabilities: Adaptations of the snowball sampling technique using social media. *Journal of Pediatric Health Care, 33*(1), 107-110. https://doi.org/10.1016/j.pedhc.2018.09.011

Li, N., Chan, E., & Peterson, S. (2019). The economic burden of depression among adults with rheumatoid arthritis in the United States. *Journal of Medical Economics, 22* (4), 372-378. https://doi.org/10.1080/13696998.2019.1572015

Lim, J., Choi, S., Lee, W., Jang, J., Moon, J., Kim, Y., & Kang, D. (2018). Cognitive-behavioral therapy for patients with chronic pain. *Medicine, 97*(23). http://dx.doi.org/10.1097/MD.0000000000010867

Low, J. (2019). A Pragmatic Definition of the Concept of Theoretical Saturation.

Sociological Focus, *52*(2), 131–139. https://doi-org/10.1080/00380237.2018.1544514

Lynch, S. (2018). Looking at compassion fatigue differently: Application to family caregivers. *American Journal of Health Education, 49*(1), 9-11. https://Doi:10.1080/19325037.2017.1369197

Matcham, F., Ali, S., Hotopf, M., & Chalder, T. (2015). Psychological correlates of fatigue in rheumatoid arthritis: A systematic review. *Clinical Psychology Review, 39,* 16-29. http://dx.doi.org/10.1016/j.cpr.2015.03.004

Merleau-Ponty, M., & Smith, C. T. (1966). *Phenomenology of Perception/by M.* Merleau-Ponty; Translated from the French by Colin Smith. Routledge.

Macon, S. (2016). Grow up Virginia: Time to change our filial responsibility law. *U.* Rich. L. Rev., 51, 265.

MacLeod, S., Tkatch, R., Kraemer, S., Fellows, A., McGinn, M., Schaeffer, J., & Yeh, C. (2021). The impact of covid-19 on informal caregivers in the US. *International Journal of Aging Research, 4(3),* 87-87.

McDermott, E., & Mendez-Luck, C. A. (2018). The processes of becoming a caregiver among Mexican-origin women: A cultural psychological perspective. *SAGE Open*, *8*(2), https://doi.2158244018771733.

McGilton, K., Vellani, S., Yeung, L., Chishtie, J., Commisso, E., Ploeg, J., Andrew, M., Auyala, A., Gray, M., Morgan, D., Chow, A., Parrott., Stephens, D., Hale., L., Keatings, M., Walker, J., Wodchis, W., Dube., McElhaney, J., & Puts, M. (2018). Identifying and understanding the health and social care needs of older adults with multiple chronic conditions and their caregivers: a scoping review. *BMC Geriatrics, 20*(1), 145. https://doi-org/10.1186/s12877-020-01552-5

McGrath, C., Palmgren, P. J., & Liljedahl, M. (2019). Twelve tips for conducting qualitative research interviews. *Medical Teacher*, *41*(9), 1002-1006.

Milano, M. D. (2017). *Exploration of the Lived Experiences of Chronic Pain Sufferers:* An Interpretative Phenomenological Investigation (Doctoral dissertation, Northern Illinois University).

Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative Data Analysis: A Methods Sourcebook*. 3rd. *ed: Sage*.

Mohammadi, S., DeBoer, M., Sanderman, R. & Hagedoorn, M. (2017). Caregiving demands and caregivers' psychological outcomes: The mediating role of perceived injustice. *Clinical Rehabilitation, 31*(3), 403-413. https://doi:10.1177/02692155/6643846

Morelli, N., Barello, S., Mayan, M., & Graffigna, G. (2019). Supporting family caregiver engagement in the care of old persons living in hard to reach communities : A scoping review. *Health and Social Care in the Community, 27,* 1363-1374. Doi :10.111/hsc.12826

Moustakas, C. (1994). *Phenomenological Research Methods.* Sage.

Murphy, L. B., Cisternas, M. G., Pasta, D. J., Helmick, C. & Yelin, E. (2018). Medical expenditures and earnings losses among US adults with arthritis in 2013. *Arthritis Care & Research, 70*(6), 869-876.

National Alliance for Caregiving and AARP Public Policy Institute . (2015). *Caregiving* *in the US*. Retrieved from https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf

National Association of Social Workers. (2017). *Code of Ethics*.

Naushad, N., Dunn, L., Munoz, R., & Leykin, Y. (2018). Depression increases subjective stigma of chronic pain. *Journal of Affective Disorders, 229,* 456-462. https://doi.org/10.1016/j.jad.2017.12.085

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-based Nursing*, *18*(2), 34-35. https://doi:10.1136/eb-2015-102054

Nowakowski, A., & Sumerau, J. (2017). Out of the shadow: Partners managing illness together. *Sociology Compass, 11,* 1-12. https://doi.org/10.1111/soc4.12466

Ojeda, B., Salazar, A., Duenas, M., Torres, L., Mico, J. & Failde, I. (2014). The impact of chronic pain: The perspective of patients, relatives and caregivers. *Families, Systems, & Health, 32*(4), 399-407. https://dx.doi.org/10.1037/fsh0000069

Otero, P., Torres, Á., Vázquez, F., Blanco, V., Ferraces, M., & Díaz, O. (2019). Does the disease of the person receiving care affect the emotional state of non-professional caregivers? *Frontiers in Psychology*, *10*. DOI: 10.3389/fpsyg.2019.01144

Oxhandler, H. K., & Pargament, K. I. (2018). Measuring religious and spiritual competence across helping professions: Previous efforts and future directions. *Spirituality in Clinical Practice, 5*(2), 120. https://doi.org/10.1037/scp0000149

Pfefferbaum, B., & North, C. S. (2020). Mental health and the Covid-19 pandemic. *New England Journal of Medicine, 383*(6), 510-512.

Pitcher, M., Von Korff, M., Bushnell, M., & Porter, L. (2019). Prevalence and profile of high-impact chronic pain in the United States. *The Journal of Pain*, *20*(2), 146-160. https://doi.org/10.1016/j.jpain.2018.07.006

Potter, C., Kelly, L., Hunter, C., Fitzpatrick, R., & Peters, M. (2017). The context of coping: A qualitative exploration of underlying inequalities that influence health services support for people living with long-term conditions. *Sociology of Health & Illness, 40*(1), 130-145. Doi:10.1111/1467-9566.12624

Pryma, J. (2017). "Even my sister says I'm acting like a crazy to get a check:" Race, gender, and moral boundary-work in women's claims of disabling chronic pain. *Social Science & Medicine, 181*, 66-73. https://dx.doi.org/10.1016/j.socscmed.2017.03.048

Reinhard, S. & Young, H. (2019). Family caregivers are members of our team. *American Journal of Nursing, 119*(11), 7-8.

Reynaert, D., Dijkstra, P., Knevel, J., Hartman, J., Tirions, M., Geraghty, C., Gradener, J., Lochtenberg, M., & van den Hoven, R. (2019). Human rights at the heart of the social work curriculum. *Social Work Education*, *38*(1), 21-33.

Robinson-Lane, S. & Vallerand, A. (2017). Pain treatment practices of community-dwelling Black older adults. *Pain Management Nursing*, *19*(1), 46-53. https://doi.org/10.1016/j.pmn.2017.10.009

Roth, W. M. (2015). Analyzing the qualitative data analyst: A naturalistic investigation of data interpretation. In Forum Qualitative Sozialforschung/Forum: *Qualitative Social Research,* 16(3). http://dx.doi.org/10.17169/fqs-16.3.2415

Ruben, M., Blanch-Hartigan, D. & Shipherd, J. (2018). To know another's pain: A meta-analysis of caregivers' and healthcare providers pain assessment accuracy. *Annals of Behavioral Medicine.* https://doi.org/10.1093/abm/kax036

Ruddere, I., Goubert, L., Stevens, M., Debeugle, M., Craig, K., & Crombez, G. (2014). Health care professionals' reactions to patient pain: Impact of knowledge about medical evidence and psychological influences. *The Journal of Pain, 15*(3), 262-270.

Salehi-tali, S., Ahmadi, F., Zarea, K., & Fereidooni-Moghadam, M. (2017). Commitment to care: The most important coping strategies among family caregivers of patients undergoing hemodialysis. *Scandinavian Journal of Caring Science, 32*, 82-91. https://doi: 10.1111/scs.12432

Santos, E., Duarte, C., Silva, J., & Ferreira, R. (2019). The impact of fatigue in rheumatoid arthritis and the challenges of its assessment. *Rheumatology, 58,* 3-9. https://doi:10.1093/rheumatology/kez351

Schatman, M. (2015). The American chronic pain crisis and the media: About time to get it right? *Journal of Pain Research, 8*, 885-887. https://dx.doi.org/10.2147/jPRS/102090

Schulz, R., Savla, J., Czaja, S., & Monin, J. (2017). The role of compassion, suffering, and intrusive thoughts in dementia caregiver depression. *Aging Mental Health, 21*(9). 997-1004. https://doi:10.1080/13607863.2016.1191057

Shugrue, N., Kellett, K., Gruman, C., Tomisek, A., Straker, J., Kunkel, S., & Robison, J. (2019). Progress and policy opportunities in family caregiver assessment: Results from a national survey. *Journal of Applied Gerontology, 38*(9), 1319-1341. Doi:10.1177/0733464817733104

Silverman, D. (2017). How was it for you? The Interview Society and the irresistible rise of the (poorly analyzed) interview. *Qualitative Research*, *17*(2), 144-158. https://doi:10.1177/1468794116668231

Sloan, A., & Bowe, B. (2014). Phenomenology and hermeneutic phenomenology: The philosophy, the methodologies, and using hermeneutic phenomenology to investigate lecturers' experiences of curriculum design. *Quality & Quantity: International Journal of Methodology*, *48*(3), 1291–1303. https://doi-org/10.1007/s11135-013-9835-3

Smith, J., Flowers, P., & Larkin, M. (Eds.). (2009) *Interpretative Phenomenological Analysis.(2nd Edition)* Sage.

Spence, D. G. (2016). Supervising for robust hermeneutic phenomenology: Reflexive engagement within horizons of understanding. *Qualitative Health Research*, 27(6), 836-842. https://doi.org/10.1177/1049732316637824

Starks, H. & Trinidad, S. (2007). Choose your method: A comparison of phenomenology, discourse analysis, and grounded theory. *Qualitative Health Research 17*:1372–80. doi: 10.1177/1049732307307031

Stenner, R., Mitchell, T., & Palmer, S. (2017). The role of philosophical hermeneutics in contributing to an understanding of physiotherapy practice: a reflexive illustration. *Physiotherapy*, *103*(3), 330–334. https://doi-org/10.1016/j.physio.2016.05.003

Stroh, K. (2015). Intersubjectivity of Dasein in Heidegger's Being and time: How authenticity is a return to community. *Human Studies, 38*(2), 243-259. doi:10.1007/s10746-015-9341

Sturgess, J. N. (2016). Drawing from Heidegger: Dasein and the question of communication. Empedocles: *European Journal for the Philosophy of Communication*, *7*(1), 23-37.doi:10.1386/ejpc.7.1.23_1

Sutton, J., & Austin, Z. (2015). Qualitative research: Data collection, analysis, and management. *The Canadian Journal of Hospital Pharmacy, 68*(3), 226. https://doi:10.4212/cjhp.v6813.1456

Thackeray, L., & Eatough, V. (2015). "well the future, that is difficult": A hermeneutic phenomenological analysis exploring the maternal experience of parenting a young adult with a developmental disability. *Journal of Applied Research in Intellectual Disabilities, 28*(4), 265-275. https://doi.org/10.1111/jar.12126

Todorova, I., Turner, H., Castaneda-Sceppa, C., Young, D., & Bonner, A. (2016). "I do it with love": Engagement in caring for people with dementia. *Global Qualitative Nursing Research, 3*, 1-14. Doi:10.1177/2333393616668634

Toye, F., Seers, K., & Barker, K. (2018). A meta-ethnography of healthcare professionals' experience of treating adults with chronic non-malignant pain to improve the experience and quality of health care. *Health Services and Delivery Research*, *17*. https://doi-org/10.3310/hsdr06170

Turner, B., Liang, Y., Rodriguez, N., Valerio, M., Rochat, A., Potter, J., & Winkler, P. (2017). Gaps in the public's knowledge about chronic pain: Representative sample of Hispanic residents from 5 states. *The Journal of Pain*, *18*(6), 628-636.

United States Department of Labor (August 7, 2020). COVID-19: Who needs to closely monitor the pandemic impact on its operations.

Uysal, A., Ascigil, E., & Turunc, G. (2017). Spousal autonomy support, need satisfaction, and well-being in individuals with chronic pain. A longitudinal study. *Journal of Behavioral Medicine, 40*(2), 281-292.

Vaughan, C., & Kluger, B. (2018). Palliative care for movement disorders. *Current Treatment Options Neurology (20)*2, 1-15. Doi 10.1007/s11940-018-0487-4

Ventura, J., & Chung, J. (2019). The lighten your life program: An educational support group intervention that used a mobile app for managing depressive symptoms and chronic pain. *Journal of Psychosocial Nursing & Mental Health Services, 57*(7), 39–47. https://doi-org/10.3928/02793695-20190221-01

Wohl, A. R., Ludwig-Barron, N., Dierst-Davies, R., Kulkarni, S., Bendetson, J., Jordan, W., ... & Pérez, M. J. (2017). Project engage: snowball sampling and direct recruitment to identify and link hard-to-reach HIV-infected persons who are out of care. *Journal of Acquired Immune Deficiency Syndromes, 75*(2), 190-197. https://doi:10.1097/QAI.0000000000001312

Zwar, L., Angemeyer, M., Matschinger, H., Riedel-Heller, S., Konig, H., & Hajek, A. (2021). Are informal family caregivers stigmatized differently based on their gender or employment status?: A German study on public stigma towards informal long-term caregivers of older individuals. *BMC Public Health, 21,* 1868. https://doi.org/10.1186/s12889-021-11955-7

Appendix A: Recruitment Announcement

Are you a caregiver for a loved one that has been diagnosed with chronic pain?

Chronic pain can be a symptom of many different diagnoses.

Many people with chronic pain symptoms need help with their Activities of Daily Living. Knowing about the experiences of caregivers of loved ones diagnosed with chronic pain could help the caregiver as well as the patient in the future, but will not have any direct benefit to the participants.

Caregivers might help patients with the following activities:

- Cooking
- Cleaning
- Personal Hygiene
- Medication
- Transportation
- Other Healthcare Needs

Location:
I will interview you over the telephone or other web based technology that will take less than an hour.

Are you eligible?

- Female
- Age 65-70
- Caregiving for a loved one diagnosed with chronic pain
- Living in the Southwestern part of the United States

If you’re unsure if you meet the requirements, call or email me:
Anne Hatfield, LCSW
Doctoral Student at Walden University

Appendix B: Semistructured Interview Questions

1. Tell me about your family/family members?

2. How does (? family member's name if already known or "someone in your family") rely on you to help him/her get things done that he/she wants to do? Probing question – Tell me about experiences you have had going to the doctor with him/her, reminding him/her about taking medications, cooking or cleaning for him/her?

3. What have your experiences been in the role of caregiver for your loved one? Probing – Tell me about ways that he/she is dependent on you?

4. Tell me about your loved one's mental health? Probing question – How does her/she rely on you when they are scared/anxious/sad?

5. How does his/her medical treatment affect you? Probing question – Tell me about what you do to help your family member with their mental health treatment and how do you feel about that? Tell me about your experiences of being involved in their health care?

6. Tell me about your communications, either in person, email, on the phone, with his/her mental health care providers? Probing question – If you have called them to ask a question or for clarification about something, what was your experience?

7. If he/she hasn't followed the mental health care provider's recommendations/advice/orders, tell me about your response? Probing question – What has your experience been with this? Do you try to handle it yourself or do you involve the medical team?

Appendix C: Recruitment Email

To: Potential Research Participant's Name
From: Anne Hatfield, LCSW

Hello! Thank you for your response. I am attempting to recruit volunteers for my doctoral research project. These volunteers are being asked to participate in an interview (by telephone or other web based technology) to better understand the experiences of female caregivers of loved ones diagnosed with chronic pain.

The following is a copy of the Consent Form for you to have in advance. This form is used to communicate with a research participant about potential risks and benefits of participating in the research project. It also includes information regarding the research process. I will email or mail a copy of it prior to the interview for you to sign.

CONSENT FORM

You are invited to take part in a research study about experiences of caregivers of family members diagnosed with chronic pain related to rheumatic musculoskeletal disease (RMD). The researcher is inviting female caregivers between the ages of 65 to 70, living in the Southwestern region of the United States, who are willing to participate in an interview.

This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named Anne Hatfield, who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to learn about your experiences of involvement in your family members' mental health care.

Procedures: If you agree to be in this study:

1. You will be asked to participate in an interview that will take approximately one hour.
2. Several days later, you will be asked to review the verbatim transcript of the interview for accuracy which will take approximately 30 minutes.

Here are some sample questions:

3. How does <u>(? family member's name if already known or "someone in your family")</u> rely on you to help him/her get things done that he/she wants to do?
4. If he/she hasn't followed the health care provider's recommendations/advice/orders, tell me about your response?

Voluntary Nature of the Study: This study is voluntary. You are free to accept or turn down the invitation. No one at Walden University will treat you differently if you decide not to be in the study. If you decide to be in the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study: Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as becoming upset when remembering things that make you sad or mad. Also, if during the research process abuse, neglect, or any criminal activity is revealed, I would be obligated to report it to the appropriate authorities.

You might benefit from this study in helping advocate for others in your similar situation. **However, there are no immediate, direct benefits or compensation to participants individually**

Privacy: Reports coming out of this study will not share the identities of individual participants. Details that might identify participants, such as the location of the study, also will not be shared.

The researcher will not use your personal information for any purpose outside of this research project. Data will be kept secure by password protection and encryption.

Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions: You may ask any questions you have now. Or if you have questions later, you may contact the researcher.

If you want to talk privately about your rights as a participant, you can call the Research Participant Advocate at my university at 612-312-1210.

Walden University's approval number for this study is 03-22-21-0520750 and it expires on March 21, 2022.

The researcher will mail a copy of this form for you to keep or it is recommended that you print a copy of this for your records if you are receiving this by email.

Obtaining Your Consent

If you feel you understand the study well enough to make a decision about it, please indicate your consent by signing below (if in person) or replying "I consent" to the email.

Printed Name of Participant

Date of consent

Participant's Signature

Researcher's Signature

I encourage you to call or email me to ask any questions that you have about the research project or the Consent Form. Your involvement in this research is strictly voluntary and you may withdraw from participating in it at any time without consequence. If you initially decide to participate, you will still be free to withdraw at any time later without any explanation for their decision to withdraw. You have the option of participating in the interview using a telephone or using other web based technology.

Also, the following questions will be asked during the interview:

1. Tell me about your family/family members?
2. How does <u>(? family member's name if already known or "someone in your family")</u> rely on you to help him/her get things done that he/she wants to do? Probing question – Tell me about experiences you have had going to the doctor with him/her, reminding him/her about taking medications, cooking or cleaning for him/her?

3. What have your experiences been in the role of caregiver for your loved one? Probing – Tell me about ways that he/she is dependent on you?
4. Tell me about your loved one's mental health? Probing question – How does her/she rely on you when they are scared/anxious/sad?
5. How does his/her medical treatment affect you? Probing question – Tell me about what you do to help your family member with their mental health treatment and how do you feel about that? Tell me about your experiences of being involved in their health care?
6. Tell me about your communications, either in person, email, on the phone, with his/her mental health care providers? Probing question – If you have called them to ask a question or for clarification about something, what was your experience?
7. If he/she hasn't followed the mental health care provider's recommendations/advice/orders, tell me about your response? Probing question – What has your experience been with this? Do you try to handle it yourself or do you involve the medical team?

Chronic pain can be a symptom of many different diagnoses, including arthritis, fibromyalgia, neuropathy, and more. Chronic pain often is better on some days and worse on other days. Individuals diagnosed with chronic pain might need help from a friend or family member to complete their activities of daily living. The individual may need help with medication, transportation, cooking, cleaning, personal hygiene, or numerous other activities that help them throughout the day.

Your time and consideration are greatly appreciated.
Anne Hatfield, LCSW