

2023

## Exploring Care Recipients' Health Conditions Influence on Caregivers and Caregivers' Meaning of Care Dependence

Yolanda Suarez-Calvo  
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# Walden University

College of Psychology and Community Services

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Walden University  
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Abstract

Exploring Care Recipients' Health Conditions Influence on Caregivers and Caregivers'

Meaning of Care Dependence

by

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MS, Capella University, 2017

MS, Interamerican University, 1989

BS, University of Puerto Rico, 1974

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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## Abstract

Little is known about the ways in which caregivers are affected or influenced by their care recipients' health conditions. Additionally, the meaning of care dependence for caregivers is also understudied. The purpose of this generic qualitative study was to examine caregivers' affection/influence due to the physical and psychosocial health conditions of the individuals for whom they care. Further, the meaning of care dependence, from the perspectives of the caregivers, was sought. The theoretical framework to further this research was Montgomery and Kosloski's (2009) caregiver's identity theory. The research question addressed the ways caregivers are affected or influenced by the care recipients' physical and psychosocial health conditions and their meaning of care dependence. Seven caregivers were interviewed for this study. Data were collected using a semistructured interview and thematic analysis led to the identification of five themes: human behavior, needs, concerns, education, and communication. The findings indicated that caregiving can negatively affect the caregivers' health from different perspectives including emotional, psychological, physical, and spiritual. The findings also revealed that care dependence's specific meaning for each caregiver was based on the caregiver's feelings for the care recipient and their perception of the caring context. The implications for a social change are related to how these findings could influence the regulation of the caregiving industry to avoid seniors and disabled persons' abuse and enhance policy development leading to caregivers and their care recipients building stronger relationships and experiencing personal growth.

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## Dedication

This dissertation is dedicated to my parents Hilda Celia and Marcelino, and my sister Ivette Laura who always believed in me. My family was my never-ending source of support, encouragement, love, and motivation. They also gave me the courage and will to pursue the path I chose to follow. Although my father is gone, his death constantly reminds me that life is precious, and that we should never give up on our dreams.

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## Chapter 1: Introduction to the Study

Population aging is an unprecedented phenomenon (Dube & Choyal, 2012; World Health Organization [WHO], 2013) leading to a societal problem (Mendez, 2013) because the number of elders who are in the need of assistance is steadily increasing. Aging persons with disabilities have promoted an increased need for caregivers and those caregivers need support. Global changes related to demographics, nutrition, and epidemiology indicate that increases of persons who are elders are related to increases with chronic illnesses and disabilities (Tavarez et al., 2020). Under these circumstances, care dependence arises because of physical weakness, age-related conditions, or disabilities limiting a person's daily activities and capacity for self-care (Roth et al., 2015). According to Boggatz et al. (2007), care dependence refers to a subjective necessity for support compensating for a self-care deficit. However, dependence is a complex phenomenon and a heavy responsibility that is experienced through feelings of guilt, insufficiency, constant concern, and worry (Piredda et al., 2020). Therefore, it is important to explore how care recipients' physical and psychosocial health conditions affect or influence their caregivers and the caregivers' meaning of care dependence (Tavares et al., 2020). This chapter will address the study's background, problem statement, purpose, research question, theoretical framework, nature of the study, definition of terms, assumptions, scope and delimitations, limitations and barriers, significance, the chapter's summary, and the organization of the remainder of the study.

### **Background of the Study**

During the aging process, the prevalence of illness and frailties increase leading to

dependence (Branchet et al., 2018). These processes promote physical, mental, intellectual, and social loss limiting older people in how they conduct their daily tasks, whether activities of daily living (ADL) and/or instrumental activities of daily living (IADL). The combination of needs arising from health conditions (i.e., dementia, arthritis, strokes, and depression, among others) implies much care and help are needed. Although dependence is a concept with various meanings, the crux of the concept is still the need for assistance. Based on the literature, elders' dependence represents a stress factor that usually entails detrimental consequences for caregivers in the care dependence relationship. Therefore, it is important to examine the lack of information on how care recipients' physical and psychosocial health conditions affect the caregivers. Studies have shown that caregivers are more susceptible to physiological and mental health effects due to the burdens mainly related to unmet needs or barriers (Gorawara-Bhat et al., 2019). Gorawara-Bhat et al. mention that two types of barriers/unmet needs frequently reported are instrumental (health information resources, access/proximity to services, organizational rigidity, and financial) and emotional (care recipient's nonadherence, communication issues with recipients/extended family, role reversal with the recipient, and caregivers support groups). The caregiver-care recipient relationship or dyad is central to the caregiving experience, acting as the context where the construction of meaning and the care dependence relationship occurs.

However, current literature indicates that dependence has strong relational connotations (Piredda et al., 2016). Although dependence may appear to be a limiting factor, it can help a person experience life more deeply by enabling the reinterpretation of

its meaning, value, and view of its essential dimensions. New perspectives can help care recipients envision themselves differently in their life, the world, and with others. Piredda et al. also mentioned that dependence can catalyze the reevaluation of small but important beautiful things that went unnoticed during a rushed healthy life. This study was needed because the insights regarding the care dependence relationship can help provide caregivers with the adequate help and support needed.

### **Problem Statement**

In many places, caregivers are usually in charge of the care of loved ones. The care dependence experience tends to add to family members' burden but also impacts the family's structure, functioning, and relationships by altering the caregivers' ability to adequately respond to their caregiving (Juntunen et al., 2018). Nevertheless, changes regarding social, demographic, nutrition, epidemiological, and financial transformations continue not only to promote the population's aging but to reduce the availability of caregivers for family care. Population aging has contributed to a new architecture of social relations leading to complex changes in family patterns and the intergenerational milieu (Paoletti & Carvalho, 2012). Social changes have challenged peoples' current priorities, family life, and even societal norms (Savy et al., 2014). Aspects of concern for caregivers relate to social providers, family-based care, social trends, generational and financial issues, and elders abuse and neglect.

When providing support to seniors, various persons (i.e., spouses, adult children, relatives, friends, and neighbors) can help with the different aspects of care (Jesmin et al., 2011). The assisting provider and the care recipient's circumstances also influence care



especially if the relationship between seniors and their adult children is neither smooth nor harmonious. However, the provision of care becomes more complicated as the demand for care goes beyond the caregiver's ability to provide care or when the caregiver is trapped having to choose between his/her needs (e.g. work, education, and/or marriage) and the caregiving responsibilities (Lowenstein, 2010).

Worldwide, family structure has undergone remarkable changes (Jesmin et al., 2011). An example is the age structure (e.g., elders outnumber children) which reduces the number of family members available to provide eldercare while increasing the family's care burden. Other examples are the delay in marriage, marital patterns (including divorce), and the generational components shaping the family into nuclear types. Households have reduced in size, decreasing the capacity for supporting older adults who are also at risk of social support (Sharma, 2013). Trends such as migration, urbanization, education, and wage labor have altered the family's structure by promoting social isolation, a decrease in eldercare, and reduced quality of life for older people (Lowenstein, 2010). As adult children leave home seeking self-support, education, and the achievement of dreams, the chances of them returning home for caregiving duties are less likely (Sharma, 2013). Therefore, to avoid endangering risks like the lack of food and shelter, loneliness, and healthcare availability among others, many adult children take their parents with them when they migrate (Jesmin et al., 2011). The physical removal of elders from their homestead makes elders more vulnerable exposing them to feelings of insecurity, stress, and anxiety.

Family caregiving may not be available to meet the increasing needs for elder

care in the future (Jesmin et al., 2011). Modern society's vision and beliefs have contributed to changes in attitudes and values across the world. According to Jesmin et al., traditional family values have been eroded and gender roles have changed worldwide. The changing societal norms about independence, individualism, consumerism, and selfishness affect the motivation to fulfill the moral obligation of eldercare (Jesmin et al., 2011; Sharma, 2013). Unpleasant attitudes toward elders have emerged, at times, due to the loss of love, respect, compassion, and courtesy by younger generations (Erickson, 2002). The persistent intergenerational conflict promotes a decrease in family support because elders are rejected, stereotyped, and seen as a burden (Penhale, 2010). Elders are also marginalized when perceived as incapable, dependent, and childlike or seen as deteriorating and dying (Bennett & Gaines, 2010).

A potential source of conflict between elders and their adult children might be financial matters. Studies have undervalued the importance of elders' financial independence in the promotion of their care and wellbeing (DeLiema et al., 2012). Various factors determine the nature and direction of the financial resources flow between seniors and their children. Related factors are the economic status of elders and their children, the quality of the relations between them, and the availability and quality of welfare services (DeLiema et al., 2012; Sharma, 2013). Inheritance is important since the cultural expectation is children care for their parents and in return, they are entitled to their parent's wealth and possessions (Sharma, 2013).

Elders' dependence represents a stress factor that usually entails detrimental consequences for caregivers in the care dependence relationship (Branchet et al., 2018;

Lu et al., 2017). Growing attention and interest exist among researchers regarding elder abuse and neglect (Jesmin et al., 2011). Although the topic is relatively unexplored, elder abuse and neglect have increased at alarming rates (American Association of Retired People [AARP], 2015). Caregivers' neglect and verbal abuse are the most common forms. The predators of elder mistreatment are usually adult children, sons or daughters-in-law, and paid home aides (DeLiema et al., 2012). Among the cited reasons for mistreatment are the generational gap, adjustment to problems, the strain generated in the caring context, women's workforce participation (DeLiema et al., 2012; Jesmin et al., 2011), and financial exploitation (AARP, 2015; Schmitt, 2015).

Finally, cultural expectations can influence the caregiver's experience. A study regarding the effect of culture on family caregivers' experiences demonstrated cultural values and norms influenced the way the caring role is perceived (Pharr et al., 2014). Care is influenced by cultural values, motivation, interests, and spirituality (Crandall, 2014; Pharr et al., 2014). According to Pharr et al. (2014), culture is a learned system of behaviors, attitudes, beliefs, values, norms, assumptions about life, and activities accepted as correct by a particular ethnic group. Therefore, the sociopolitical and environmental contexts influence the way caregivers visualize and interpret their surroundings (Maldonado, 2015) in the dependence relationship.

Piredda et al. (2016) asserts dependence is inherent in humans and is due to a relational nature, frailty, and bodily vulnerability. Several researchers identified care dependence as a complex phenomenon with multiple meanings, but very few are conscious of what it represents for needy persons (Branchet et al., 2018). In

contemporary societies, dependence is seen as a stressful situation that relates to feelings of powerlessness, worthlessness, and uselessness (Shahgholian & Yousefi, 2018).

Qualitative studies focusing on patients' experiences related to care dependence within different contexts showed dependence as a difficult experience because it was hard for patients to ask for help, and they had experienced the fear of being abandoned or punished by their caregivers (Piredda et al., 2016).

According to Smith-Carrier et al. (2019), caregiving is an intense and complicated activity where the amount and type of care given varies from one caregiving dyad to another. Even when caregiving is burdensome and can negatively influence the caregiver's physical and mental health, many caregivers still experience satisfaction in helping with the care recipient's needs and in establishing good relationships (Gorawara-Bhat et al., 2019). The act of caregiving has a specific meaning for each caregiver, but those meanings are intertwined with the caregiver's perception of the care recipient (Gorawara-Bhat et al., 2019). Subsequently, meanings infused in care dependence are said to be camouflaged (Strandberg & Jansson, 2003). Smith-Carrier et al. (2019) also mentioned that what happens between those involved in the caregiving relationship influences the meaning of care dependence. Dependence is not something to overcome because it can also serve as the means through which human growth is possible (Valdes-Stauber et al., 2018).

Although the research regarding the concept of care dependence illuminates important findings, I have found little research that has examined the influence of the care recipient's characteristics on their caregivers and caregivers' meaning of care

dependence. Given such, further research is warranted that could examine the lack of information on how care recipients' physical and psychosocial health conditions influence/affect their caregivers and the caregivers' meaning of care dependence (Tavares et al., 2020).

### **Purpose of the Study**

The purpose of this generic qualitative study is to explore how caregivers are influenced by the care recipients' physical and psychosocial health conditions and their meaning of care dependence. Branchet et al. (2018) mentioned that despite the various meanings of dependence, the need for human assistance is still the crux of the concept. Caregiving is an intense and complicated activity; therefore, it is critical to identify avenues to best support the backbone of the long-term care system. Furthermore, analysts are predicting a "caregiving cliff" by the midcentury and suggest society addresses the possible crisis (Gibson-Hunt & Reinhard, 2016).

### **Research Question**

How are caregivers influenced by the care recipients' physical and psychosocial health conditions and their meaning of care dependence?

### **Theoretical Framework**

The theory that served as the lens of the study is the caregiver's identity theory (Montgomery & Kosloski, 2009). According to the authors of the theory, the caregiving role emerges out of an existing role relationship, usually familial (such as a son/daughter, wife, or husband). In the caring context, as the care recipient's needs increase in quantity and intensity, changes begin to take place in the care dependence relationship resulting in

caregivers experiencing transitions in their identity. In addition, the caregiver's behaviors also change based on how they perceive their role with the care recipient to minimize conflicts. Caregivers must change their behaviors to align with their identity standard, change their identity standard, or change their self-appraisal or perception for it to be compatible with the circumstances.

The caregivers' identity theory helped to analyze the caregiver and care recipients' experiences by guiding the development of research and interview questions. The theory's origin will be further discussed in Chapter 2. It will also be explained how the framework relates or connects to the current study. In Chapter 5, the interpretations of the findings will be assessed through the lens of the theory when discussing the practical implications, the research recommendations, topics for future research, and the study's limitations.

### **Nature of the Study**

For this study, the generic qualitative design was chosen to explore how care recipients' physical and psychosocial health conditions impact their caregivers and the caregivers' meaning of care dependence. Sandelowski (2000) mentioned that this research design characteristics include being flexible, with no philosophical underpinning, and is focused on the participants' experiences. He also comments that the descriptions to be obtained are straight, simple answers, and with the intent of easy understanding. The information offered by participants during the interviews helped me understand the caregivers' views, ways of thinking, and actions in the working context.

Initially, the number of participants to interview was eight to ten because this

number was thought to provide enough data to saturate the study (see Morse, 1994). I sought to obtain participants who have caregiving experience, which are not only willing to share their experiences, but whose experiences are diverse to enhance richness and unique stories (see Glicksen, 2003). Therefore, a purposeful sample of caregivers was obtained using a snowball sampling strategy because they are best enabled to answer the research question. The selection of participants was made using the inclusion and exclusion criteria according to the methodology.

The two methods to be used for data collection were one-on-one semistructured interviews and observations. The interviews took place on an agreed date and time in the caregivers' natural context and lasted 45 to 60 minutes. The observations made about the participants were written as notes to help clarify the reflections and analyses since my different roles may have influenced the procedure in one way or another. Crandall (2014) mentioned that although the understandings accessed during interviews are not to be held as "truthful", they are seen to be "meaning-full". Therefore, I not only identified and examined emergent themes, but also sought meaning and interpretation of the participants' lived experiences (see Crandall, 2014).

Once data was collected, the thematic analysis was used to identify the themes inductively repeating in each interview. The purpose of the analysis was to develop a category system where the data can be tabulated in an organized and coherent manner for the findings to be explained. The benefit is the provision of the systematic and visible stages of the process through which the results are to be obtained (Lacey & Luff, 2009). To keep the participants' names confidential, identifiers including names were coded

before the analysis.

### **Definitions**

Throughout this study, the following vocabulary is used to represent the activities and roles in caregiving. The meaning of the words used are provided and the resource from which they came is noted as well.

*Activities of Daily Living:* Essential activities related to personal hygiene, (e.g., feeding, bathing, walking, clothing, etc.; Lowenstein, 2010).

*Care:* The provision of practical or emotional support (Wiles, 2011).

*Caregiving:* Psychosocial support and direct care related to illness and aging provided by an informal caregiver in the recipient's home (Cho, 2007).

*Care recipient:* Persons 65 years or older who receive care from either a formal or informal caregiver usually in their home (Cho, 2007).

*Care dependence:* Refers to the subjective necessity for support compensating a self-care deficit (Boggatz et al., 2007).

*Formal caregiver:* Paid professional (such as a nurse, physician, dietitian, therapist, or home health aide) who provides assessment, education, support, and therapeutic care to patients (Cho, 2007).

*Informal Caregiver:* A family member (spouse or adult child) that spends most of the time providing unpaid, ongoing assistance to close relatives, friends, or neighbors and who is viewed by others as the primary responsible party of the homecare (Cho, 2007).

*Instrumental Activities of Daily Living:* Assistance with activities related to tasks supporting independent life, e.g., shopping, meal preparation, house cleaning, telephone



calls, finances, and transportation among others (Lowenstein, 2010).

### **Assumptions**

Assumptions are unexplained beliefs. They are important because they help describe the phenomenon dealt with and help determine if conclusions can be correctly drawn from the results of an analysis (Mitroff & Bonoma, 1978). This study was designed to investigate the impact the care recipients' health conditions have on their caregivers and the caregivers' meaning of care dependence. The significant focus of caregivers' perspectives on coping and adapting directly emphasizes that caregivers need to be able to effectively cope to better help their aging and disabled care recipients. A first assumption was that due to overpopulation and aging, there will always be chronic and disabled care recipients with cognitive problems and caregivers who are unable to successfully cope with the circumstances.

Another assumption was that when using a qualitative approach to understand how care recipients' characteristics impact their caregivers and the caregivers' meaning of care dependence, the information to be collected is best told by the caregivers themselves. Qualitative research focuses on the participant's experiences and acknowledges the researcher's role as an analyst and interpreter who recognizes their preconceptions of the phenomenon. During the interview, the rapport established with the participant leads to a close relationship allowing open communication and enhancement of the storytelling (Gringeri et al., 2013).

I also assumed that journaling and field notes helped explain my observations, emotions, filtering, and insights (see Lavety, 2003). My field notes and journaling may

have offered details to help clarify the reflections and analysis of ideas or interpretations about the participant's responses due to my different roles, which can influence the procedure in one way or another (see Creswell, 2009). Field notes and journals are valuable assets for qualitative research.

Despite the type of research, an important expectation has to do with the honesty in the responses. Therefore, it is assumed that the caregivers' responses to the interview questions were honest and sincere. In addition, it is unlikely that any instrument could ever offer a valid, reliable, and trustworthy assessment of the information provided because the caregivers may either exaggerate or withhold information.

### **Scope and Delimitations**

The scope of the study relates to the way care recipients' health conditions influence their caregivers and the caregivers' meaning of care dependence because there is little research on the topic. Smith-Carrier et al. (2019) mentioned that caregiving is an intense and complicated activity where the amount and type of care given varies from one caregiving dyad to another. Even when caregiving is considered burdensome and can negatively influence the caregiver's physical and mental health, many informal caregivers still experience satisfaction in helping care recipients with their needs and in establishing good relationships (Gorawara-Bhat et al., 2019). However, the act of caregiving has a specific meaning for each caregiver, but meanings are intertwined with the caregiver's perception of the care recipient, and this is the reason for which care dependence is said to be camouflaged (Strandberg & Jansson, 2003).

Participants were chosen based on specific criteria. The aim was to obtain

participants who had lived the experience (the focus of the study), wanted to share their experiences, and were diverse to enhance richness and unique stories (Glicken, 2003). The study was limited to participants who are adults (21 years of age or older) of both genders and who were caregivers of an aging adult at the time of the study or who had provided care in the past. Participants excluded from the study were persons under 21 years of age and who lacked caregiving experience.

Lincoln and Guba (2000), and Mertens (2005) suggested that to address external validity, a qualitative researcher should examine the transferability of the data to other populations. The population under study is aging persons with disabilities and/or chronic diseases as opposed to children with disabilities or malformations. Other theories/conceptual frameworks related to the area of study are social constructionism which provides a philosophical lens through which caregivers' experiences may be viewed and understood. As mentioned by Crandall (2014), under this social constructionist umbrella, symbolic interactionism and social role theory can provide a theoretical framework allowing the researcher to explore ways in which caregivers describe their experiences of caregiving and identify how the caring role has influenced their quality of life. While symbolic interactionism provides a lens through which to explore what the caregivers perceive as meaningful experiences, the social role theory provides a way to explore the caregiver's perception of his/her role and the effect of that role whether affecting or enhancing his/her quality of life (Crandall, 2014). Although generalizability is not a goal of qualitative research, human services fields that could benefit from this study are nursing and education.

### **Limitations**

The interview protocol could have influenced the interview process (Hernández et al., 2003). This limitation was resolved through a field test because it can offer feedback for the revision and refinement of the interview questions. In addition, a possibility for bias also existed because the interpretations of the results could be influenced by my background (Giorgi, 1992). For such reason, I kept a reflective journal and field notes to acknowledge past experiences and observations to clarify doubts.

Regarding sample size, a general guideline in qualitative research is to study a few individuals because the qualitative approach seeks to gather in-depth, detail-rich information. The method's intent is not to generalize or transfer information but to elucidate the particular and the concrete (Creswell, 2018; Glicken, 2003). Therefore, to focus on the characteristics of the population of interest best enabled to answer the research question, the number of participants I sought to interview was eight to 10 because they may provide enough data to saturate the study (Guest, Bunce & Johnson, 2006). Additionally, participants for recruitment were not easy to access (Hernández et al., 2003).

The qualitative research design is very useful when exploring a phenomenon, learning new insight, and/or intensely investigating a phenomenon (Leedy & Ormrod, 2005). Qualitative research involves an interpretive, subjective approach instead of a systematic, objective approach leading to challenges regarding its scientific usefulness (Leedy & Ormrod, 2005; Mertens, 2005). Researchers suggest that qualitative research is useful for addressing complex questions like those attempting to understand human

behavior and interaction with the environment (Creswell, 2018; Miles & Huberman, 1994).

Qualitative methods may also lead to potential limitations. This study used one-on-one, face-to-face interviews that led to limitations like (a) the participants' reaction to the questions and/or me, (b) bias on behalf of the myself, as well as the participants, and (c) participants may have interpreted the terms and questions differently (Crandall, 2014; Yin, 2007). During the use of qualitative methods, it is the investigator's responsibility to ensure the quality, accuracy, trustworthiness, and credibility of the data gathered during the interview (Creswell, 2018; Glathorn & Joyner, 2005). Therefore, I made use of member checking, careful transcription of interview data, and triangulation (Hernández et al., 2003; Yin, 2007).

### **Significance**

This study is significant in that it helps explain the care dependence relationship. The study may provide better insights into the caregivers' meaning of care dependence and can help caregivers as well as care recipients to not only build stronger relationships but also experience personal growth. The study can also provide information to organizations like the American Association of Retired People [AARP] (2015), which is fighting for the regulation of the caregiving industry to avoid abuse of seniors and disabled persons. In addition, this study may encourage policy development within the government by understanding caregivers are more than a "tool" to the care recipient's health (Gibson-Hunt & Reinhard, 2016). Caregivers, as agents of change, make use of their natural capacity to transcend (go beyond themselves) to help the care recipients

based on their needs in their natural context (Piredda et al., 2020).

### **Chapter Summary**

The life expectancy of the disabled adult population is lengthening well into their 50s (American Geriatrics Society, n.d.; Crandall, 2014). The situation is due to two major phenomena: overpopulation and aging (Dube & Choyal, 2012; WHO, 2013) which have promoted a societal problem (Mendez, 2013) because more elders are in the need of more assistance. Care recipients' chronic conditions and/or disabilities will continue to affect their caregiver's wellbeing. Therefore, to address this problem, I interviewed a purposive sample of seven caregivers to explore and discover how care recipients' health conditions influence or affect their caregivers and the caregivers' meaning of care dependence. The theoretical framework which consists of the caregivers' identity theory served as the lens to understand the changes caregivers go through to cope, adapt, accept, and internalize the caring role.

In the following chapters of this study, a detailed review of the research conducted will be described. Chapter 2 will address the conceptual framework and a review of the critical literature on caregiving and topics related to the concept of care dependence which will be discussed in detail. In Chapter 3, I will discuss the methodology employed and the research design chosen compared to other research methods that were considered, but not selected. Then Chapter 4, will describe the data collected from the selected participants and provide an analysis of that data. Based on the data analysis, I will then be able to report the research findings of this study. Finally, Chapter 5 will address the interpretation of the results, and include a discussion of the

practical implications, the research recommendations, topics for future research, and the study's limitations.

## Chapter 2: Literature Review

The lack of understanding of the concept of care dependence poses concerns about the wellbeing of caregivers regarding the provision of adequate help and support (Khalaila & Litwin, 2011). To address the lack of understanding, this generic qualitative study sought to explore the following research question: How are caregivers influenced by the care recipients' physical and psychosocial health conditions of their caregivers and the caregivers' meaning of care dependence? Chapter 1 addressed the background of the study and the issues underlying the research problem. Chapter 2 will offer the literature search strategy, the conceptual framework, the review of the critical literature, and the chapter summary.

### **Literature Search Strategy**

The library databases and search engines used for the search of peer-reviewed articles were Academic Search Complete, ERIC, ProQuest Central, SAGE Journals, and Walden University's Thoreau multi-database. The iterative process consisted of using the following keywords or terms: *care dependence*, *caregivers* and *dependency*, *the meaning of dependence*, *care*, and *caregivers*, and *caregiving* and *identity* in different combinations. The search sought to obtain current peer-reviewed articles that provided information about the care dependence concept.

### **Theoretical Framework**

Montgomery and Koslowski's (2009) caregiver's identity theory served as the lens and foundation to understand the caregiving career. In this theory, the caregiving career is seen as a series of transitions resulting from changes in the caring context (e.g.,



changes in the care recipient's health condition or changes in activity patterns). As mentioned by the authors, the caregiving role originates from a previous relationship role, usually familial, which involves either a spouse or adult children. In the caring context, the caregiver establishes the initial relationship with the care recipient and brings along their views and expectations about the duty concerning the provision of care. However, over time as the recipient's needs increase in quantity and intensity due to their limitations, changes in the dependence relationship begin. The caregiver will not only start to feel distressed and suffer changes in behavior but will also view their role with the care recipient differently because the caring tasks required to maintain the recipient's health become inconsistent with the caregiver's initial expectations. The caregiver's self-view and the caring tasks collide due to the meaning the caregiver attaches to the tasks. Therefore, shifts in identity occur due to the significant changes taking place with the care recipient's increasing level of dependency. Feelings like distress and burden will continue to generate a tense situation resulting in an immediate reconciliation to relieve the caregiver's pressure. The changes in the caregiver's identity process, which are neither smooth nor continuous, will alternate between periods of stability and instability. Small adjustments will continue to occur until the caregiver copes, adapts, accepts, and finally internalizes the caring situation as the new role.

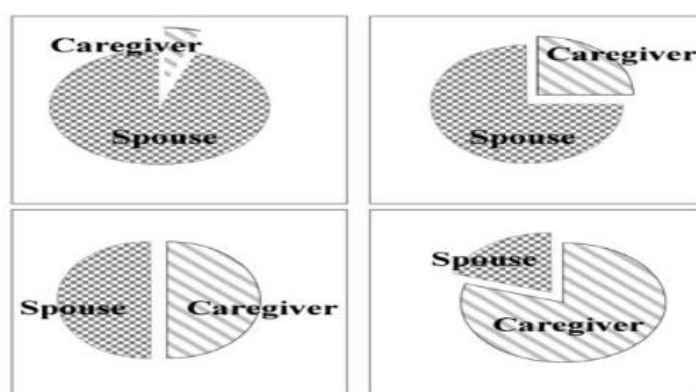
### **Identity Phases and Implications**

The caregiver's identity changes entail five phases of accommodation according to Montgomery and Koslowski (2009). In Phase 1, the caregivers begin to perform activities never previously experienced as part of the familial role. In Phase 2, the

caregiver realizes that the caregiving activities are going beyond the scope of the initial family role. These activities involve assistance with personal grooming causing some discomfort. At this point, the identification as a caregiver starts to develop. Phase 3 may require activities where caregivers and care recipients are not comfortable and may cause the caregiver to leave. For caregivers who persist, caregiving accounts for 50% of the role relationship. Identity is negotiated since the caregiver struggles between the initial identity and the new one. During Phase 4, caregiving requirements increase leading to further shifts in identity, and caring dominates the role relationship. In Phase 5, the care recipient is changing the setting and formal caregivers take over the primary responsibility. This arrangement allows informal caregivers to recover a good part of the original caregiving identity. Figure 1 shows the way of viewing the “typical” course of caregiving, although differences in the routes each caregiver’s career takes do exist.

### Figure 1

*Changing Identity of a Caregiver Possible Phases of Accommodation*



*Note.* Adapted from “Caregiving as a process of changing identity: Implications for caregiver support,” by R. Montgomery and K. Koslowski, 2009, *Journal of the American Society on Aging*,

33 (1), 51.

For Montgomery and Koslowski (2009), the great variability among caregivers suggests that caregiving is an idiosyncratic process. This conclusion has important implications because (a) any caring situation is always unique; (b) caregivers experience great differences regarding the level of pressure to accept the caring role, their expectations about the duties obligated to perform, and the circumstances allowing them to relinquish the role; and (c) most important, the caregiver role emerges from an existing role relationship which is a transformation from a previous role (Dilworth-Anderson, 2002).

### **The Theory and Research**

Caregiving, like other social behaviors, is governed by norms and social rules. According to Connell and Gibson (1997), a person's ethnic and cultural background influences the caregiver's expectations because each culture has its own rules or ethos about caring responsibility. Pharr et al. (2014) and Haley (1995) mentioned there are families whose rules determine the family members who are responsible for the care, the types of care to expect, and the conditions under which seeking outside help might be appropriate.

In the interpretative phenomenological study completed by Pharr et al. (2014) with African, Asian, and Hispanic American cultures, the data indicated that all three groups experienced difficulties in caregiving. However, among all three groups, there were significant differences in the cultural values and norms shaping the caring experience. The differences were categorized as cultural embeddedness where caregiving

is so embedded in the life experience of some groups that caregiving is done without question. Regarding cultural determinants, in cultures with a collectivistic orientation, the caregiving role is prescribed based on a set hierarchy of “who” is to care for and/or the traditional gender ideology. For cultural values and norms, the maintenance of harmonious relationships with others is paramount; saying “no” is viewed as a rejection and abandonment. Pharr et al.'s study highlighted the cultural mandate regarding the provision of care in the African, Asian, and Hispanic American cultures.

In a literature review conducted by Eifert et al. (2015), the authors sought to determine the major themes related to the development of the caregiver’s identity. The findings suggested multiple factors are related to the development of the family caregiver’s identity. The first theme is the role engulfment and reversal which occurs when the role of the caregiver and the responsibilities of caring begin to consume a person leaving barely time for other activities and behaviors that may have helped define the person previously. The person’s identity, which is reshaped by the loss of former roles and the development of new ones, gradually starts to feel pressure as the caregiver role intensifies. Persons who do not change their identity as a caregiver see previous identities fade away or become less relevant due to caring responsibilities. According to Miller et al. (2008), two factors influencing the caregiver’s identity are (a) the parent-child structure because of the role reversal and (b) the competence structure having to do with the “it had to be done” attitude of caregiving. This suggests the variety of tasks engulfing persons and making them feel more like a parent than a child. The second theme is the loss of a shared identity, also known as a person’s dyadic identity. This

identity refers to the identity that develops due to the relationship between caregiver-care recipients (where it is spoken of “us” or “we” instead of “I”). A third theme relates to family obligation and gender norms, where obligation and moral expectations dictate who is to care and how. Although caregiving is considered a feminine practice, Kirsi et al.’s (2000) findings hint males provide caregiving also (p.159). Fourth, is the theme of extension of the former role which relates to societal expectations and relationships. Since caregiving is seen as normal and natural for spouses and/or adult children, these persons do not feel obligated to care because previous roles played a part in the caregiver’s identity development. For example, Carpenter (2012) found that a caregiver who saw herself as the central person in her mother’s life and intended to maintain the relationship, that relationship became a critical component of her identity. The relationship helped solidify her role as her mother’s care provider and her identity as a caregiver. Finally, is the theme of the development of the master identity which occurs when the caregivers’ role becomes the dominant identity replacing or overtaking any other identity. At this point, others recognize and refer to the person as a caregiver. Moore and Gillespie’s (2014) findings suggested that the caregiver’s binding leads to delayed development in identity because others fail to acknowledge the care provider was indeed a caregiver.

The ability to focus on a situation and act toward a goal achievement represents an important aspect of psychological flexibility (Lloyd et al., 2013). Flexibility in a caregiver’s identity development should be a valuable contribution to maintaining healthy aspects of mental and physical health. Savundranayagam and Montgomery (2010)

conducted a study with 358 spouse caregivers of which 68% were females and 32% were male caregivers. In their cross-sectional study conducted through telephone interviews, Savundranayagam and Montgomery found that discrepancies between the caregiver's perceptions about the caring role mediated the relation between stressors and different types of burdens assessed in their study. Although helping with ADL activities may seem a burden to those not caregiving, these only related to burden when viewed by caregivers as going beyond her role expectations. Savundranayagam and Montgomery also found that certain problem behaviors (like aggression and wandering) were more stressful for caregivers than helping with ADL activities even when exceeding the role expectations.

Friedman and Buckwalter's (2014) study with 533 older adult caregivers (male and female) were assessed, and the caregivers included spouses and adult children. The sample was ethnically diverse including 12 % Black from Caribbean Islands, 30 % Cuban, and 18% from other Hispanic countries. From the in-home interviews conducted, the researchers found that women provided more care than men, were more stressed than men, and had more depressive symptoms than men. Women were more emotionally attached to the care recipient and appeared to be less flexible in adjusting to the caregiver role compared to men. Accordingly, as the role demands increased, female caregivers' provision of care became emotionally and physically exhaustive. Women received less social support because they did not ask for help, but also less help was offered (Brank & Wylie, 2014). It looks like female caregivers were in a disadvantaged position and maybe such a situation also explained why some caregivers reported experiencing the "loss of self" (Skaff & Pearlin, 1992).

There are few studies on caregivers' identity development and flexibility (Shifren, 2017). However, the studies have provided information on how changes in identity (or their lack) can affect the caregiver's ability to provide care and maintain health. Perhaps a reason for so few studies on caregivers' identity development has to do with the limited options for assessing the construct which is no simple task because it is multidimensional. Although a challenging endeavor, it would be worth the effort by helping to better understand factors that may benefit the caregivers.

### **The Rationale for the Caregiver's Identity Theory**

The caregiver's identity theory was appropriate for this study because it helped explain the series of identity transitions caregivers may experience due to changes in the caring context. In addition, it may also help explain how identity transitions may promote different behaviors in the caregivers, especially when influenced by either perceptions and/or interpretations of societal expectations, norms, and values affecting human behavior. Meanings developed within the context of multiple realities and factors will not only contribute to the development of self and identity, but also to the fulfillment of the roles associated with that identity (Crandall, 2014; DePoy & Gilson, 2012; Newman & Newman, 2008). In addition, the more consonant an identity is with the social role and the expectations of society, the more likely the individual will continue in the role (Crandall, 2014; Eagly, 2009; Turner & Stets, 2006; Lincoln & Guba, 2000). The findings of this study may help the existing research by identifying new factors associated with burden and quality of life against depression and anxiety to help with the prevention.

### **Literature Review Related to Key Variables and/or Concepts**

The aging of the population is a historically unprecedented phenomenon (Dube & Choyal, 2012; WHO, 2013). As mentioned by Illés (2013), two main population challenges worldwide are over-population and aging. In the 21st century, aging has led to problems affecting all aspects of life like social, demographic, and economic transformations which have promoted an ever-reduced number of available caregivers for family care (Gibson Hunt & Reinhard, 2016). Tavares et al. (2020) mention there is a wide variety of reasons why people require care for their relatives and commented that three of five care recipients have a long-term physical condition (59%), more than a third have a short-term physical condition (35%), and about a quarter have memory problems (26%)” (p.65). Tavares et al. (2020) also commented that 37% of care recipients suffer from more than one ongoing problem or illness such as Alzheimer's, dementia, surgery/wounds, cancer, mental health, intellectual disability, or musculoskeletal conditions to mention a few (Eifert et al., 2015). This kind of situation, whether acute or chronic, usually requires the help of a caregiver.

### **Caregiving and Caregivers**

Caregiving refers to the psychosocial support and direct care related to illness and aging given by an informal caregiver in the care recipient's home (Branchet et al., 2018; Eifert et al., 2015; Salazar- Maya et al., 2020; Tavares et al., 2020). Although not a new phenomenon, care implies alleviating human suffering guided by motives of respect, love, and compassion (Erikson, 2002). It entails the dependence on another person to carry on the essential activities of daily living (ADL) related to personal hygiene and the



instrumental activities of daily living (IADL) which are tasks supporting independent life (e.g., grocery shopping, finances, transportation) (Gorawara-Bhat et al., 2019; Henskens et al., 2019; Lowenstein, 2010; Navarro-Sandoval et al., 2017; Salazar-Maya et al., 2020; Tavaréz et al., 2020). Caregiving requires knowing the recipient's needs, characteristics, and preferences to allow a long-term relationship influenced by lifestyle, culture, and face-to-face contact (Lowenstein, 2010). Besides the feelings of emotional closeness, the sensitivity to others' needs is important to an adaptive, and healthy caring alliance (caregiver-care recipient) known as a dyad where an empathic relation takes place toward acceptance, treatment, and rehabilitation (Ramírez-Perdomo et al., 2018; Sanchez & Carrillo, 2017). Caregivers of disabled persons usually take on two roles: assistant and protector (Pope, 2013). While caregivers seek to reward the benefits received from their loved ones, care recipients avoid becoming a “burden” by seeking a significant experience and cordial relationship to take place in the dyad (Ramírez-Perdomo et al., 2018). Therefore, to encourage informal caregiving, legislation promoted the Family Medical Leave Act of 1993 and the Older Americans Act Amendments in 2000 to establish the creation of the National Family Caregiver Support Program (Crandall, 2014; Gibson Hunt & Reinhard, 2016).

The informal caregiver is the person from the care recipient's social network who is the main responsible party for his/her care. This person, usually a family member (spouses and/or adult children), spends most of their time providing unpaid care, usually has no specific training, and most likely a female is viewed as the main responsible person for the homecare, the physical and emotional support, the decision making, the

care recipient's health, and who also helps with the financial support (Barbosa et al., 2011; Dixie & Querido, 2020; Eifert et al., 2015; Gans, 2013; Gorawara-Bhat et al., 2019; Ramírez-Perdomo et al., 2018). According to Shahgholian and Yousefi (2018), the word "care" has a variety of meanings (e.g., protection, attention, the lookout on, wellbeing, and watching for someone among others). However, from the care recipient's perspective, the concept emerges or reveals in the form of empathy, social support, concern, and companionship.

Caring for another person demands a constant cognitive, emotional, and physical effort. The care for aging persons leads to stress and negative outcomes such as burdens that can impact not only the caregiver's health and wellbeing but also the care recipient (Dixie & Querido, 2020; Eifert et al., 2015; Gorawara-Bhat et al., 2019; Lu et al., 2017). The distress and/or burden experienced by the caregiver is linked to the care recipient's health condition and behavioral problems (Branger et al., 2018; Morrison et al., 2020; Ramírez-Perdomo et al., 2018). Most alarming, caregivers experience an increased mortality rate and are at a greater risk for abusing the care recipient because of stress and burden (Eifert et al., 2015). The understanding of care recipients' behaviors may contribute to better relationships. According to Azoir-Hui et al. (2010), improper behaviors may be heightened in situations with disabled persons particularly when the care recipient becomes distressed. The provision of help or assistance depends on how the negative behaviors displayed are attributed. Attributions about a situation could lead to positive (pity or sympathy) or negative (anger or disgust) emotions (Azoir-Hui et al., 2010). In situations in which attributions favor positive moods, caregivers will be

inclined to provide help but when dealing with negative feelings and problem behaviors (due to a long-standing personality or behavioral pattern), the caregiver will be reluctant to assist. Therefore, caregivers' attributions can affect or influence the quality of the relationship with their care recipient depending on the care recipient's type of disability (Azoir-Hui et al., 2010). Caregivers of disabled persons with a disease or congenital condition are less inclined than caregivers of persons with an acute acquired disability to attribute problem behaviors to matters of personal control, responsibility, or will (Zehner & Walker, 2014). During caregiving, the acutely acquired disability is associated with maladaptive attributions and caregivers' distress. To avoid risks related to chronic illness, burnout, and financial challenges, caregivers use factors like social support, competencies, networking, problem-solving skills, positive coping strategies, and the finding of meaning and purpose to develop better relationships with the care recipient to improve the quality of life (Berry et al., 2012; Eifert et al., 2015; Morrison et al., 2020; Tavarez et al., 2020).

### **The Development of Identity**

Identity is of particular interest because it influences behavior (Eifert et al., 2015). The development of identity is complex and socially constructed. It is believed that identity develops from the interaction of a person's psychobiological aspects and social context (Kroger, 2006). People use social categories like qualities, beliefs, personalities, and look to describe themselves and develop a stable identity structure. The identity structure is to help regulate and govern people's lives by "providing a sense of self-continuity and a frame of reference for making decisions, problem-solving, interpreting

experience, and self-relevant information” (Berzonsky et al., 2011, p.295). Then, people get to know themselves by interacting with others and understanding how others see them (Erikson, 1968). Identity is not fixed but continues to develop and evolve (Berzonsky et al., 2011). Therefore, life experience promotes identity evaluation, reconfiguration, and change (Cross et al., 1991). As Banaji and Prentice (1995) suggested, identity changes result from major changes in the role and situational demands.

Erikson and Marcia’s work helped understand the development of identity (Shifren, 2017). Erikson (1968, 1980) mentioned that identity refers to the aspect from which a person develops the sense of whom he/she is and how he/she fits in the world by considering the choices offered within a culture, occupation, sexual orientation, beliefs, and values. Marcia (1966, 1993), on the other hand, differentiated four types of identity statuses or states of ego development. These are identity achievement that involves a period of exploration followed by a commitment to a particular goal, action, or decision, identity foreclosure commits without any exploration of alternatives goals, actions, or decisions, identity moratorium has to do with the exploration of alternatives goals, actions, decision, but not committing, and identity diffusion involves no exploration and no commitment. Shifren (2017) comments on the importance of parents and their parenting styles regarding the development of a person’s identity. The number of experiences available for persons to have a healthy role model relates to the importance of social expectations. Like Erikson, Deaux (1993) mentioned that identity formation includes two dimensions: (a) the personal identity or self which is reflexive and includes the traits and behaviors that are self-descriptive and associated with at least one identity

category, and (b) the social identity or role which occurs if acknowledged and supported by others.

According to Lindenberg and Staudinger (1998), and Shifren (2017), human beings can also adapt to change and modify the performance of their abilities. The ability to adapt to change known as “plasticity” or flexibility has been described as the key principle of lifespan development. However, not all researchers agree with the idea of plasticity over the lifespan because humans become more rigid as they age. Researchers who have studied continuity and change in the perception of self in late life have found that most of their samples (adults aged 85 years old and over) perceived themselves as the same over time (Troll & Skaff, 1997). Thus, researchers using a neuroscience framework suggested that persons with healthy brains show a cognitive shift in the way their identity is regulated. Although persons may have identity changes, the identity will be more continuous with age due to the decrease of a capacity limiting the brain to allow the changes in identity. This means, there is a reduction in the level of plasticity. Therefore, the brain will not be able to accommodate new information into the existing networks and consequently, people will end up with a more rigid identity. Researchers also agree that some level of plasticity in the brain is essential for survival and healthy development. Individuals with more flexibility can manage situations better, and better flexibility is associated with better mental health (Lloyd, et. al., 2013). Whitbourne (1986) found that age predicted identity flexibility and mentioned that older participants adapted to their current situations and were able to accept the constrain of age. Nevertheless, education and employment have an important role because these two

aspects influence persons by favoring changes. It is widely acknowledged that people have multiple identities, grounded in the occupancy of multiple roles and diverse group memberships. Multiple identities may reinforce or conflict with each other (Stryker & Burke, 2000). The self-identification as a caregiver may be related to people's expectations about whether one should assume the caring role (Hughes et al., 2013).

Adapting to ever-changing environments is most apparent in caregiver roles (Shifren, 2009). Research shows that approximately 66 million caregivers (i.e., 29% of the U.S. adult population) currently provide or have provided care to a relative, friend, or associate (The National Alliance for Caregiving and AARP, 2009). A recent study indicates that an estimated prevalence of caregiving for an adult is 16.6% (39.8 million Americans) who are primarily female caregivers (60%) with an average age of 49 years old (The National Alliance for Caregiving and AARP Public Policy Institute, 2015). There is also an estimate of 1.3 to 1.4 million young caregivers in the U.S. who experience the role of caregiver in childhood and/or adolescence (Hunt, Levine & Naiditch, 2005), and 3.6 to 5.5 million individuals between the ages of 18 to 29 years old were reported as caregivers in a national survey on young adult caregivers (Levine et al., 2005). Although informal caregiving continues to be a crucial part of health and social care provision, persons experience personal and role conflict during the transition into the role and identity of a caregiver due to the amount of burden implied.

### **Burden-Related Factors and Feelings**

Societal changes have promoted an increase in dependent persons needing support. As mentioned by Dixie and Querido (2020), the performance of this role may

not only lead to the caregiver's burden but also exhaustion. The characteristics and needs of the care recipients and the evolution of their health condition are associated with the caregiving level and nature, besides the caregiver's qualities and motivation for caring based on training, information, psychosocial support, and the relation between work and care (Bouget, Spasova, & Vanhercke, 2016; Carretero, Stewart & Centeno, 2015). Caring for another person requires a constant effort and may harm the caregiver's health. Identifying the factors associated with the caregiver's burden could help with the prevention (Cabral et al., 2013). Factors related to the care recipient are the degree of dependence, psychological health, and sociodemographic characteristics. Factors associated with the caregiver are sociodemographic characteristics (age, gender, education, and experience), the type of needs, duration of care, degree of kinship, and psychological health (Dixie & Querido, 2020; Zhu & Jiang, 2018). Strategies for caregivers to improve are self-efficacy and communication with the care recipient. Among the strategies to prevent burden and exhaustion are rest, psychoeducational interventions, cognitive-behavioral therapy, training, information on how to provide care (Vandepitte et al., 2016), counseling, and personal care services (like home health and adult day care centers). To decrease tension, Eifert et al. (2015) suggested the sharing of the care responsibility or respite. In a dyad, good relations are of extreme importance, therefore, caregivers need to avoid aggressive behaviors, abuse, mistreatment, and the care recipient's neglect (Carretero & Garcés, 2011).

While caregivers seek to make up for the benefits received from their loved ones, the recipient struggles to avoid becoming a "burden" to achieve a significant experience

in the dyad. Care recipients frequently feel guilty and frustrated about the hardships they understand are being imposed on their caregivers and/or relatives (McPherson, Wilson & Murray, 2007). Studies exploring the wish to hasten death (WTHD) have found that the feeling of being a burden may trigger WTHD. In a qualitative meta-ethnography study by Rodriguez-Prat et al. (2018), the findings suggest that for dependent care recipients' two indicators of multidimensional suffering are the feeling of being a burden and the wish of being a burden. The analysis of the feeling of being a burden helped identify two themes (a) the personal dimension and (b) the social dimension. The personal dimension relates to the emotional and psychological effects of an advanced or chronic illness, and its impact on the care recipient's sense of identity. The disease processes (physical deterioration, loss of function, incontinence, and cognitive impairment among others) affect the sense of self (Lavery et al., 2001). When care recipients perceive themselves as a burden, emotional and psychological responses develop in addition to feelings of guilt, helplessness, uselessness, and loss of self-esteem (Sitel et al., 2010). The loss of independence (or autonomy) is devastating because it causes care recipients to experience a loss of identity and meaning in life (Nissim, Gagliese, & Rodin, 2009). The sense of being devalued is related to the loss of dignity when treated like an object, the loss of control over their lives, or when their decisions are not respected (Coyle & Sulco, 2004; Lavery et al., 2001). The social dimension, on the other hand, has to do with the impact of illness because for some care recipients' functional deterioration is accompanied by the fear of dragging their loved ones into the end-of-life process. Other care-dependent care recipients' wish to die was attributed to the fear of being seen as vulnerable and frail



(Mak & Ewyn, 2005).

### **Care Dependence**

During the aging process, chronic conditions and/or disabilities increase, entailing frailties and leading to dependence (Branchet et al., 2018). The loss of physical, mental, intellectual, and/or social aspects limits aging persons from conducting their daily tasks and requiring outside help. The scientific literature usually refers to dependence as a stress factor with detrimental consequences for caregivers. Nevertheless, despite the various meaning of dependence, the need for human assistance is still the crux of the concept (Branchet et al., 2018).

According to Ramírez-Perdomo et al. (2018), as aging persons give up their independence and become dependent, they experience concern, fear, and stress. When care recipients become aware of the bodily changes, they begin to feel useless, vulnerable, powerless and mistrust their body's capacity, skills, health, and ability to work. Caregivers recognize the fragility to which care recipients are exposed due to their health condition and understand how harsh circumstances can become because dependence leads to anger and stress. Nevertheless, time and the sharing of care transform the dyad into a close relationship where both members get to understand the importance of the support and care provided. While the circumstances refrain the caregiver from abandoning the recipient, the caregiver ends up isolated limiting his/her social life, neglecting his/her health, increasing the homecare, and ending up overloaded (Liljeroos et al., 2014). The caregiver could also experience anxiety, stress, and emotional problems like depression that shows through a variety of symptoms (e.g., the

desire to cry, irritability, fatigue, sadness, lack of concentration, sleeping problems, and headaches) (Navarro-Sáncdoval et al., 2017; Salazar -Maya et al., 2020). The dyad becomes an important entity because it prevents its members from perceiving themselves as a “burden” (Bierhals et al., 2017), making use of coping strategies like spirituality and religiosity. Spirituality is considered internal energy that connects to the environment. It serves as a source of inspiration, connection, and energy promoting life's altruistic feelings or can also be viewed as a personal vision that helps retain values and harmony (Torkenaes et al., 2015). Religiosity influences human behavior and wellbeing. Both aspects, which relate to health, healing, sickness, and death are crucial to care because they provide meaning and purpose during difficult situations (Nemati et al., 2017; Newberry et al., 2013).

Dependence is a complex concept with multiple meanings. In the past, dependence was considered a distressing experience due to regression and powerlessness (Piredda et al., 2016) and its strong impact on the quality of life (Candela et a., 2020). Care recipients feel powerless because of the progressive loss of autonomy, freedom, and the regression to early developmental stages (Piredda, 2015). However, qualitative studies have contributed to a different perspective. Nowadays, dependency is viewed as a key characteristic of human beings due to its relational nature, frailty, and vulnerability of the bodily condition (Colombetti, 2013). The openness of human beings to those in need relate to humans' innate capacity to go beyond themselves in helping others, that is, to self-transcend (Frankl, 1985). Piredda et al. also explained that the meaning of care dependence lies in becoming aware a person can be both: an object and a subject of care.

The object of care is the person needing help from others, while the subject is the person who can see others' needs. In either case, dependence can be viewed as a limited situation allowing life to be experienced more deeply, by reinterpreting its meaning, value, and envisioning life's essential dimensions. Therefore, dependence is to function as an enzyme, by catalyzing the reevaluation of small and important beautiful things that went unnoticed in a rushed and healthy life. Coping with dependence requires some strategies like asking for help and trusting others.

### **The Construction of Meaning**

Humans characterize by relationality. Human beings not only depend on one another, but they also need to stay connected with other humans to be recognized as valuable persons, develop their identity, feel loved, and live a meaningful life (Candela et al., 2020). Thus, meaning and purpose are central to life but more so when caring for someone with an incurable condition (Cherry et al., 2019). Since caring relatives experience a similar or higher level of distress than that of an ill family member, they are burdened with care efforts and psychological strain throughout the progression of the disease, and experience loss as anticipatory grief. According to Popek and Hönig (2015), the distress in relatives is still unrecognized, underreported, and undertreated due to negative emotions (e.g., hostile interaction patterns, emotional expressions, and tendencies of high conflict). Nevertheless, meaning in life (MiL) refers to the order, coherence, and purpose of one's existence, the pursuit and attainment of goals, and the accompanying sense of fulfillment (Reker, 2000). Existential approaches emphasize the importance of meaning. Meaning is one of the relevant factors supporting quality of life.

It protects from depression and anxiety (Scheffold et al., 2014), and promotes resilience in a “limit situation” (Valdes-Stauber, 2016). ‘Meaning in life is associated with concepts of palliative care like caregiver’s quality of life, burden, distress, and coping strategies. A strong or stable sense of meaning in life could positively influence resilience in a limited existential situation protecting the caregivers against demoralization. Sources of meaning could constitute an important resilience factor for caregivers, who must cope with the burden of care and anticipatory grief. Therefore, the meaning in life could balance the sense of impotence (e.g., terminally ill family members) in addition to reducing the sense of guilt due to negative feelings (e.g., helping relieve personal burden) (Valdés-Stauber et al., 2018; Tang et al., 2013).

According to Cherry et al. (2019), meaning relates to the making of sense, order, or coherence out of one’s existence. Caring for someone can foster caregivers’ resilience, protect their wellbeing, and promote care sustainability. Quinn et al. (2013) identified two sources of meaning which could motivate caregivers to care: first, the sense of the continuity of the dyad, and second, the caring process itself. However, what remains unclear is why some caregivers derive meaning from caregiving while others do not. Quinn et al. also performed a qualitative study using a purposive sample of 20 caregivers and three processes through which caregivers could find meaning from care which were identified as: (a) perceptions of symmetry, (b) maintenance of the sense of self, and (c) social connectedness.

In the first process, perceived relationship symmetry, the term symmetry describes what is understood as right within the context of the life cycles and the

relationship with the care recipient (Quinn et al., 2013). In symmetrical relationships, although caregiving may have not been chosen, it is viewed as right and fair. For some caregivers, the unfairness lies in the recipient's health condition and had things been different the care recipient would have cared for them. For others, caregiving is a way to reciprocate the previous care offered by the care recipient. The perception of caring as symmetrical enables the relationship to flourish and continue, instead of abruptly ending it upon either a diagnosis or progression of the care recipient's health condition. By contrast, in asymmetrical relationships, caring characterizes by feelings of intrusion, unfairness, or resentment.

In the second process, maintenance of the sense of self, the caregivers' sense of self is congruent with their self-image (Quinn et al., 2013). They employ temporal, spatial, behavioral, or cognitive strategies to structure the caregiving relationship and avoid overwhelming their sense of self. While some caregivers try not to affect life areas like social life, others see caregiving as a temporary limit to accepting the inevitable death of their loved one. In this way, caregiving becomes a time-limited process and helps accept the temporary and reversible shifts of the self-identity and normative expectations that come along with it. Caregivers who could not limit the relationship looked at care as intrusive or struggled to see caregiving as a temporary role, experiencing feelings of isolation, powerlessness, and solitude attributed to a never-ending caring process.

In the last process, perceived social connectedness, caregiving is inherently a social process (Quinn et al., 2013). Contact with others is seen as mutually supportive

and characterized by shared values, ideas, social expectancies, and experiences. The relationship includes the caregivers' sense of belonging at a societal level, the meaning fitted as a caregiver within their social world, and the experience of mutually supportive and satisfying interactions with others. The interactions included family support and relationships arising from the caregiving (e.g., engagement with support groups or internet forums). Two main benefits of social connectedness were: first, being able to seek information, help, reassurance, advice, or support when needed, and second, the normalization of caregiving that empowered caregivers to challenge instances of stigma and derive meaning from care. Thus, some caregivers were socially isolated due to care demands making social connectedness difficult which led to feelings of not belonging as a caregiver in society (Cherry et al., 2019).

### **Chapter Summary**

Limited research has been conducted examining the concept of care dependence. The current research indicates there is a lack of information on how care recipients' physical and psychosocial health conditions influence their caregivers and the caregivers' meaning of care dependence. Caregiving is an intense and complicated activity where the amount and type of care given varies from one caregiving dyad to another (Smith-Carrier et al., 2019). The act of caregiving has a specific meaning for each caregiver, but those meanings are intertwined with the caregiver's perception of the care recipient (Gorawara-Bhat et al., 2019). For this reason, care dependence is said to be camouflaged (Strandberg & Jansson, 2003). Dependence is not something to overcome because it can also serve as the means through which human growth is possible (Valdes-Stauber et al., 2018).

For this study, the generic qualitative design was chosen, and its characteristics include being flexible, with no philosophical underpinning, and focused on the participants' experiences. The descriptions to be obtained are straight, simple answers, and with details of easy understanding (Sandelowski, 2000). The information offered by participants during the interviews will help them understand the caregivers' views, ways of thinking, and actions in the caregiving context.

Chapter 3, the Methodology chapter, addresses the sampling process, design, and theoretical framework to guide the research proposal. Chapter 4 offers the analysis of the qualitative data obtained from interviews, transcribed data, and researcher journal notes. Chapter 5 will include the interpretation and discussion of the analyzed data besides the limitations, practical implications, and recommendations for future research. All the literature works, and studies mentioned in this study are cited, referenced, and included at the end of the study.

### Chapter 3: Research Method

The purpose of the study is to explore how caregivers are influenced by the care recipient's physical and psychosocial health conditions and their meaning of care dependence. In this chapter, I address the research design, the rationale of the study, and the role of the researcher. In addition, the methodology of this study is addressed and includes details about the participants, the recruitment criteria, the data collection and analysis procedures. Further, I discuss the issues of trustworthiness and describe the ethical aspects employed to reassure participants' privacy and confidentiality.

#### **The Research Design and Rationale**

This study was guided by the following research question "How are caregivers influenced by the care recipients' physical and psychosocial health conditions and their meaning of care dependence?" Qualitative research was used to gain a deep understanding of the problem. For this research, the generic qualitative design was chosen because it is characterized by the lack of philosophical underpinning, promotes flexibility (for it allows perspectives, tones, and strategies from other approaches, as a combination of techniques), and has a focal point as participants' lived experiences (Kahlke, 2014; Sandelowski, 2000). Generic qualitative studies allow researchers to play with the boundaries, making use of the tools established within a methodology to develop research designs that fit their epistemological stance, discipline, and research questions. Merriam (2002) suggested that generic studies, like any qualitative design, are epistemologically social constructivist and seek to understand how people interpret, construct, or make meaning from their world and their experiences.



The generic research design was chosen for pragmatic reasons. Its dealings were based on practical considerations because researchers may find themselves caught within the limits of an established methodology. This qualitative inquiry investigated people's reports about their subjective opinions, attitudes, beliefs, or reflections on their experiences of things in the world (Percy et al., 2015). The generic inquiry also differentiates from other qualitative designs (like case study, ethnography, grounded theory, and phenomenology) as mentioned by Percy et al. based on the focus of the study, the content of information desired, or the kind of data to be obtained that does not fit in other designs.

Mertens (2005) mentioned three reasons for choosing a qualitative approach to research. These are the researcher's worldview, the research question, and practical reasons. This study's worldview related to the caregiver's identity theory (Montgomery & Koslowski, 2009) which explained how the changes in identity experienced by the caregivers promote the construction of their reality and how that reality affects their quality of life. According to Eifert et al. (2015), people perform a variety of tasks that grounds them within the bounds of the familial relationship, but the gradual deterioration of their loved ones leads them to reconsider their identity. As caregivers construct their reality, symbols, roles, values, expectations, and norms that become internalized, they give meaning to their way of life as caregivers (Crandall, 2014).

Qualitative research uses various perspectives to best address the research question (Creswell, 2009; Glicken, 2003; Mertens, 2005). The inductive logic for qualitative research allowed the exploration of meanings, characteristics, descriptions,

and concepts through strategies like interviews, observations, conversations, recordings, and field notes (Creswell, 2009; Glicken, 2003; Mertens, 2005). In comparison to the quantitative approach which deals with numbers or measurement of things, qualitative research offered a framework to explore a phenomenon for deeper meaning by examining the “what, how, when, and where of a thing – its essence and ambiance” (Crandall, 2014, p. 295).

For practical reasons, the qualitative approach was chosen to provide caregivers a forum to address their needs for adequate help and support (Mertens, 2005; Montgomery & Koslowski, 2009). Qualitative research offered me the opportunity to become absorbed in the data collection process regarding the responses and observations of the participants (see Leedy & Ormrod, 2005). To understand the caregivers’ daily activities of caring for chronic and/or disabled adults, I asked the caregivers to share their subjective opinions by describing their struggles and successes. Mertens (2005) also comments that, if a population is studied in a quantitative way, like with statistical aggregates, the conclusions can be sterile and lack the depth of what it means to be human. Therefore, to properly address the research question and fulfill the purpose of this study, the best approach was a qualitative generic approach.

### **The Role of the Researcher**

In qualitative research studies, the researcher performs several roles. Acknowledging myself as a researcher, I served as the instrument for data collection and analysis. In my role as the interviewer, my relationship with the participants was empathic and open to understand not only how caregivers feel but also to learn and

perceive some of the different emotions they experience day by day. As an observer, I monitored the participants' gestures and body language and interpreted the meanings attached during the interview. My field notes helped clarify the information gathered from the participants and described the data during the thematic analysis. During the interview, I was a good listener to capture the details brought to my attention and made sure the information provided was accurately written. My responsibility as a data collector, analyst, and interpreter required patience, perseverance, and diligence because the thematic analysis is an iterative process that can lead to exhaustion and fatigue. Bias can exist due to my background as a caregiver. I have past experiences as an adult caregiver of chronically ill and disabled parents, relatives, and friends. Thus, I kept a reflective journal and field notes to help clarify the complexity of the participant's views and descriptions. Nonetheless, my key role as a researcher was to ensure that all ethical and legal practices regarding human rights were maintained throughout the study. In addition, I made certain that the study also adhered to the practices, procedures, and ethical guidelines approved by the university's Institutional Review Board (IRB).

## **Methodology**

### **Participant Selection and Recruitment**

Participants were chosen based on specific criteria. The inclusion criteria consisted of adults (21 years of age or older) of both genders who were current caregivers of an aging adult or who had provided care in the past. The aim was to collect data from the participants who had lived the experience of caregiving and could provide diverse details of their unique stories (Glicken, 2003). Participants excluded from the study were

persons under 21 years of age and lacking caregiving experience. As potential participants made the initial contact with the researcher by phone or email, they were screened. They were asked some questions to ensure compliance with the research criteria. Questions related to age, experience as caregivers, and the characteristics of the care recipients they assisted.

The recruitment of participants took place using the snowball technique and purposeful sampling. Friends, neighbors, and relatives referred initial participants. Thereafter, participants who contacted the researcher help spread the word about the study (Hernandez et al., 2003). It was believed that such sampling was best because it allowed the recruitment of participants who shared the same experience or phenomenon and could help achieve a good sample of participants from those who were either hesitant or unwilling to participate. Caregivers could either provide the researcher's contact information to other known caregivers or offer the researcher other caregivers' contact information for the researcher to contact them. The combined use of purposeful and snowball sampling increased the effectiveness and efficiency of recruiting eligible participants (Griffith et al., 2017; Patton, 2015). Once potential subjects contacted the researcher, they were screened and in meeting the participant's requirements, those who agree to be part of the study were invited to participate. At a set date and time, a face-to-face meeting was scheduled to review and sign the informed consent form that the IRB requires in the participant's natural context. Participants' were offered a copy of the informed consent form for their records. Then, the interview was conducted in the caregiver's natural context. Otherwise, due to COVID-19, the informed consent was sent

to the participant by mail or e-mail and after the participant returned it, the interview would take place either by teleconference, skype, or phone and be digitally recorded with the participant's permission.

### **Sample Size and Justification**

Qualitative research studies require few individuals for research. The qualitative approach seeks to gather in-depth and detail-rich information, besides helping to clarify specific details (Hernández et al., 2003). However, the sample size relies on what the researchers want to know, the purpose of the study, the resources available, and what the data will be used for (Patton, 2015). Creswell (2018) and Guest (2006) recommend that five to 25 participants should be interviewed. According to Morse (1994, 2002), a few individuals are required to ensure the focus on the characteristics of the population of interest who are best to answer the research question. Therefore, the number of caregivers interviewed were seven because they could provide enough data to reach saturation (Morse et al., 2002). Saturation refers to the moment when new information is not obtained during the interview, and the redundancy signals the researcher the data collection should cease because further attempts are unnecessary and become a waste of time (Creswell, 2018; Glick, 2003; Hernandez et al., 2003). Although the saturation point varies from one study to another depending on the qualitative design used (Fusch & Ness, 2015), it determines the sample size and indicates adequate data has been collected for a detailed analysis.

### **Data Collection Process**

The researcher was responsible for the data collection (Hernández et al., 2003).

Conducting interviews for this study was preferred because it uses a natural inquiry orientation. In an interview, openness is critical to the exchange of ideas with few direct questions asked. The aim was to keep close to the lived experience of the participants and to look for not only what was said, but what was said between the lines (Hernández et al., 2003; Glicken, 2003). The caregivers met with the researcher to interview at a set date and time in a location either chosen or preferred by them. Comfortable settings usually stimulate participants to be forthcoming and willing to cooperate with the study. The researcher made use of a face-to-face semistructured interview for data collected. There was also note-taking for clarification purposes on perceived feelings and personal impressions. As the stories were elicited, the responses offered by the participants were digitally recorded with a Sony ICD-PX333 digital voice recorder for all details to be captured. The researcher remained open to unfamiliar and unexpected responses allowing time for an exchange of dialogue when necessary. This mode of data gathering is effective because detailed-rich descriptions can be obtained (Creswell, 2018). The data collection process occurred in a quiet, safe place ensuring privacy, trust, and confidentiality. Each interview lasted 45 to 60 minutes and was guided by the interview protocol. Once the interviews concluded, the information was coded pre-analysis and stored in a secure location to maintain confidentiality. The data obtained was protected with the use of web-based cloud storage and a secured data storage device (pen drive). These steps were taken to keep the data from being lost, stolen, or compromised due to computer theft, improper data saving, or computer malfunction (Glathorn & Joyner, 2005). The pen drive was stored in a secure and locked location for at least five years.

My dissertation committee and I have access to all information gathered during the interview. The information was stored in a cloud and a pen drive for five years and then destroyed.

### **Instrumentation**

For the qualitative approach, I became the instrument of the study. The interviews were guided by the interview protocol I designed (Appendix A) for the study because qualitative researchers are reluctant to use or rely on questionnaires prepared by other investigators (Hernández et al., 2003). The interview protocol I created consisted of seven broad open-ended questions ensuring consistency from one interview to another. Additional information, obtained from each caregiver, related to demographics about their age, gender, education, socioeconomic level, and years of experience. As the instrument of the study, I used the following questions to collect the data from the participants:

- What motivated you to become a caregiver? Describe your relationship with your recipient and how you feel about it.
- How is the communication between you and your care recipient?
- Tell me about your care dependence experience when helping a care recipient.
- Describe your care recipient's physical and psychosocial health conditions.
- How do these health conditions influence or affect your caregiving?
- What meaning does the care dependence relationship have for you? Describe your experience.
- Please provide any additional information you would like to share with me

about your caregiving experience.

After the interview, the raw data obtained was placed in a cloud and saved on a pen drive. Each participant's audio recording was identified with a code. Each audio recording was then transcribed into text through a sound organizer and converted by me to a Microsoft Word (MS Word) document to ensure accurate and credible information. Member checking was done because the information offered by the participant needed to be verified directly with the participant to ensure comprehension. The raw data was eventually submitted to manual thematic analysis.

### **Data Analysis Process**

The thematic analysis identified the themes inductively repeating in each interview. The purpose of the analysis was to develop a descriptor or category system where the data could be tabulated in an organized and coherent manner for the findings to be explained (Maguire & Delahunt, 2017). The benefit was the provision of systematic and visible stages of the process through which the results were obtained (Lacey & Luff, 2009). The thematic analysis is a six-step procedure (Maguire & Delahunt, 2017). The first step of the process is familiarization which was to locate, identify relevant raw data, and obtain a thorough overview of all the data collected. The raw data is not systematically linked to the research question or structured according to the theory (Glaser & Laudel, 2013) therefore, step two known as thematic coding or indexing was used. Codes or labels help identify common sentence structures, related topics, and repetitive patterns (Yin, 2012). In step three, the generation of themes occurred, and the coding was done by going through all the text labeling words, phrases, and paragraphs.



Codes that were repeated or related in meaning were collapsed into a category helping reduce the data and to identify the final research themes. Step four was related to the review of themes, helping ensure that the themes found were useful and accurate representations of the data. The naming of themes in step five involved defining each theme and determining its meaning by figuring out how they contributed to understanding the data. Finally, step six is the report, where the findings were displayed in a thematic chart showing the main themes obtained from all participants, the related codes, and sub-codes.

### **Issues of Trustworthiness**

A critical aspect of qualitative research is the capability of the content analysis to support the research argument. While reliability ensured consistency and stability in the researcher's procedures across various studies, internal validity spoke to the extent to which the research design and the data it yields allowed me to obtain accurate conclusions about the sample or population being studied (Hernández et al., 2003; Leedy & Ormrod, 2010). Both reliability and internal validity were ensured through rich descriptions and prolonged time in the field. Reliability was also enhanced through fieldnotes and the use of a digital recorder (Hernandez et al., 2003).

Credibility relates to how vivid and faithful descriptions are regarding the lived experience (Creswell, 2018; Glicken, 2003). Strategies to ensure internal validities are triangulation which verifies evidence from different sources like different persons or sources of data and member checking where the information is verified with the participant to ensure comprehension (Leedy & Ormrod, 2010; Morse et al., 2002;

Shenton, 2004). The use of the interview protocol, the interview recordings, and the immediate transcription of the data provided the path to address the credibility (Hernández et al., 2003; Sandelowski, 2000) as a means of triangulation. The caregivers' descriptions of their experiences offered a solid foundation of details including time, place, and context from where credibility and accuracy can be sought for comparison. Qualitative research involves few individuals needed for the study. The method's intent is not to generalize or transfer information to other contexts or populations, but to elucidate the particular and the concrete (Hernández et al., 2003). Lincoln and Guba (2000), and Mertens (2005) suggested that to address external validity a qualitative researcher should examine the transferability of the data to other populations. Transferability requires the provision of enough detail of the context to allow the reader to decide if the prevailing environment resembles contexts, he/she is familiar with and whether the findings can justifiably be applied to the other settings (Morse et al., 2002; Shenton, 2004).

Dependability is important because it establishes the research study's findings as consistent and repeatable. Two strategies related to dependability are external audit and triangulation. Both strategies help confirm the accuracy of the findings and to ensure the findings are supported by the data collected (Morse et al., 2002; Shenton, 2004). An external audit involves an outside researcher who examines and assesses the processes of data collection, data analysis, and the results of the research study. Triangulation relates to the convergence of information from different sources to better understand the phenomenon (Creswell, 2018; Leedy & Ormrod, 2010). All interpretations and conclusions were examined to determine if they were supported by the data itself.

Confirmability has to do with the level of confidence in the research findings based on the participants' responses and words instead of potential researcher biases. Confirmability seeks to verify that the findings are shaped more by participants instead of the researcher (Morse et al., 2002; Shenton, 2004). Two techniques to be used are audit trail and reflexivity. The audit trail details the process of data collection, analysis, and interpretation. The topics recorded are to be unique and interesting for data collection, as the information about coding and the rationale for merging the codes, and the explanation of the themes meaning. Reflexivity refers to my attitude when collecting and analyzing the data. I must consider my background and position to determine how these two aspects could influence the research. For this reason, I made use a reflexive journal or diary to annotate my ideas (Glatthorn & Joyner, 2005; Glicken, 2003).

### **Ethical Considerations**

Before recruiting participants and collecting data, I obtained approval from Walden University's IRB (approval number 03-02-22-1022023) . Participants were never pressured to participate. Participating in the study was entirely voluntary, and the participants could withdraw from the study at any time. The interview responses offered were held in the strictest confidence (Leedy & Ormrod, 2010) and the participants' names were coded to avoid personal data being compromised. The codes assigned corresponded to each participant's initials and interview sequence (e.g., PSM1, ILS2; Glatthorn & Joyner, 2005; Hernández et al, 2003).

The risks related to the study were not foreseen, however, in case of a medical emergency 911 would immediately be contacted. The population to be interviewed were

caregivers and the nature of the inquiry favors emotional responses. I was ready to recommend the professional services of a qualified counselor in case of an emotional outburst. Throughout this research study, no monetary compensation was offered. In addition, anonymity, participants' privacy, and confidentiality was respected. Even though caregivers are not considered a vulnerable population, if potential abuse or neglect of either a caregiver or care recipient had been discovered during the data collection process, the appropriate authorities would have been contacted and notified.

The data obtained is protected with the use of web-based cloud storage and a secured data storage device (pen drive). These steps were taken to keep the data from being lost, stolen, or compromised due to computer theft, improper data saving, or computer malfunction (see Glathorn & Joyner, 2005). The pen drive will be stored in a secure and locked location for at least 5 years.

### **Chapter Summary**

This study sought to explore and understand how the care recipients' health conditions influence/affected their caregivers and the caregivers' meaning of care dependence. The generic qualitative approach used seven caregivers of adult care recipients with chronic illness and/or disabilities. Montgomery and Kozlowski's (2009) Caregiver's Identity theory served as the methodological framework to address the research problem. A purposive sample was used to solicit participants who were knowledgeable regarding caregiving and care dependence. Once Walden University's IRB approval was granted and participants came forward or were located to participate in this study, the informed consent documents were provided. Upon participants' signing of

the informed consent, the researcher started the one-on-one audio-taped interview process. The digitally recorded data was transcribed into a Word document to undergo a manual thematic analysis. In addition to the recordings, this researcher kept field notes about non-verbal communication, the interview setting, and the time. Credibility, accuracy, and transferability were addressed through member checking, a complete summary of the data collection and analysis, and the coordinated transcribed data emerging themes. The findings will be presented and discussed in chapter four.

## Chapter 4: Results

The purpose of this generic qualitative study was to explore how caregivers are influenced by the care recipients' physical and psychosocial health conditions and their meaning of care dependence. This study sought to answer the following research question: How are caregivers influenced by the care recipients' physical and psychosocial health conditions and their meaning of care dependence? This chapter presents the setting and demographics of the participants interviewed to answer the research question. The participants' demographics were described to highlight their relevance to the study. In addition, I also describe how the participants were recruited, the data collection and analysis procedures, the findings, and the evidence of trustworthiness.

### **Setting**

Participants were recruited using the snowball technique (a chain referral sampling; Glickens, 2003; Hernandez et al., 2003). Though 10 caregivers were desired to participate in the study, the final sample size was seven caregivers. From the group of participants, I recruited five through people with whom I had an existing relationship and after explaining to them what the study was about, they agreed to participate. The other two participants approached me based on the information offered through the word of mouth of other participants; after I provided them the information about the study, they also decided to join as participants. For these participants, there were no personal, organizational, or any conditions influencing them or their experience to either affect or alter the interpretation of the study's results.

## Demographics

The sample for this study included seven participants. While I had initially recruited 10, two of the participants were eliminated because they did not meet the research criteria and one chose not to participate when signing the informed consent, reducing the sample size to seven participants. The chosen group included one male and six females who met the criteria to participate in the study. The participants became the purposeful sample of the study because they had direct and personal knowledge of the events of interest and could provide first-hand information to answer the research question. Participants' ages ranged from 42 to 81 years of age and all belonged to the middle socioeconomic class (MSC). Their education ranged from high school (HS) to a master's degree (MS) and their experience as caregivers varied from 4-41 years. A summary of the participant's demographic information is denoted in Table 1.

**Table 1**

*Participants' Demographics*

Participants	Age (years)	Gender	Education	Socioeconomic Status (SS)	Experience (years)
1	81	F	BS	MSC	20
2	67	F	BS	MSC	18
3	62	F	BS	MSC	4
4	42	F	HS	MSC	25
5	69	F	MS	MSC	41
6	50	M	BS	MSC	13
7	77	F	HS	MSC	13

### Participant Descriptions

A brief overview of each participant is offered to help with the understanding of the findings.

- *Participant 1.* This participant was a schoolteacher for several years. Her relatives' needs led her to become a caregiver since they had no one else to care for them. Her husband had Alzheimer's, her mother had dementia, and her aunt diagnosed with chronic heart problems assessed her faith, determination, and goodwill.
- *Participant 2.* Executive secretary who worked for 15 years at a prestigious pharmaceutical company. She became her mother's caregiver because arthritis deformed her body seriously limiting her walking, the lifting of her arms, and the handling of articles over one pound.
- *Participant 3.* This professional took care of her mother with osteoarthritis, COPD, and respiratory problems despite her mom's strong character. She also took care of her aunt who had symptoms of dementia.
- *Participant 4.* This nurse assistant took care of her four siblings when her father died, and her mother left the home seeking a job. During her caregiving, she was taught by nurses and physicians which allowed her to gain some experience in the healthcare field. She has been working for several years in nursing homes with seniors diagnosed with different health conditions.
- *Participant 5.* This participant has been a nun for 44 years. At the religious order's schoolhouse, she oriented orphan girls on how to organize themselves, to care about their hygiene, and taught them various courses. Since this participant lived outside the metropolitan area and both of her parents were disabled seniors, her religious order granted her permission to stay home for their care and from



there continue her clerical work. To better serve her parents and due to the family's financial situation, she became a physical therapist and took upon her mother's therapies. She also offered chromotherapy to caregivers during the afternoons.

- *Participant 6.* This single parent lives with his 12-year-old son. He worked as a manager at a prestigious company serving the Caribbean. He and his mother became the family caregivers since his father lost both hands and ended up severely injured in an explosion while on duty. In addition, the participant's youngest brother was born with two conditions: morbid fat and Parker-Willis syndrome (where the brain never receives the message to stop the food intake after eating reason for which the patient becomes obese). These situations forced this participant to become a caregiver and a financial provider.
- *Participant 7.* Participant 7 is a fiction writer who has published several books. Her love for her family made her set aside her writings to take care of her husband with severe COPD and her 19-year-old son who ended up brain-damaged in an accident and eventually died in a coma.

I conducted seven semistructured interviews. Two of them took place in a community library and the other five were over the phone, all completed over a period of three months. The data was gathered from seven open-ended questions which served as the interview protocol. All seven participants were given enough time to ask questions about the study and resolve any doubts. I digitally recorded the interviews after the signing of the informed consent.

## **Data Collection**

The data collection process began on March 17, 2022, after approval was granted by Walden University's IRB (approval number 03-02-22-1022023). The information about the study was spread among friends and relatives by word of mouth in the state of Florida. The recruitment was finalized on May 3, 2022, after the completion of the seventh interview.

### **Data Collection Process**

I collected data from seven participants who volunteered to be in the study and who were never coerced or given an incentive to participate. Each interview lasted 45-60 minutes after the informed consent was signed and all doubts or questions were resolved. Five interviews were done over the phone after the informed consent was received, and the other two face-to-face interviews took place in a study room at the community library. Participants were asked seven open-ended questions (see Appendix A) which served as the interview protocol. I digitally recorded each interview using a Sony ICD-PX333 digital voice recorder after verbal and written consent was obtained from each participant. The data was transcribed ad verbatim.

### **Data Analysis**

Qualitative research follows a linear, hierarchical, and organized approach (Lacey & Luff, 2009).). The thematic analysis promotes a descriptor (category) system where the data can be tabulated in an organized and coherent manner for the findings to be explained. This analysis is inductive and linked to the Caregivers Identity theory (Glazer & Laudel, 2013).

Data in an inductive analysis can be independently analyzed because it allows the data to fit into categories or themes which emerge through the data. Therefore, once each interview was completed, I transcribed the recordings into a word document and validated the transcripts for accuracy by comparing the transcripts with the recordings. After obtaining a thorough overview of the data collected from each participant, I examined themes, patterns, and inferences as I reviewed the data using Glaser and Laudel's (2013) indexing of themes. I then highlighted statements and phrases which appeared meaningful to produce a list of themes for each interview. I also reviewed the data's relevance to the research question by evaluating the relation of the statements and phrases previously highlighted to the research question. The statements and phrases that were found not to be related to the research question were eliminated from the data analysis but kept in a separate word document for possible future use. In addition, I clustered data that appeared related to one another (similar meaning themes) and described each group by a name for easy identification. This led me to develop a master table of themes to consolidate the themes across the group of respondents. The clustered themes were compared to the original transcript to ensure that the participant's meaning was captured correctly. This step, in the process, is where the interpretations of the meanings of the responses within the transcript take place while cross-checking the interpreted meanings with what the participant said (Glaser & Laudel, 2013). I also organized the familiar common text to produce sub-codes from the identified codes per theme since meaningful data was obtained from the shared responses. Finally, the analysis of the raw data produced five main themes: human behavior, needs, concerns,

education, and communication. These findings were displayed in a thematic chart (Table 2) showing the main themes obtained from all participants, the related codes, and sub-codes.

### **Evidence of Trustworthiness**

Results trustworthiness were established through credibility, transferability, dependability, and confirmability. Credibility was established through member checking. I prepared a transcript review and e-mailing each participant a copy of their transcribed interview. The transcribed interview gave each participant the opportunity to verify the accuracy of my transcription of the data (Leedy & Ormrod, 2010; Morse et al., 2002; Shenton, 2004). Participants confirmed the transcripts were an accurate reflection of their responses.

To address generalizability, a qualitative researcher needs to examine the transferability of the data to other populations (Lincoln & Guba, 2000; Mertens, 2005). To aid in this process, I offered information on the sampling method, research design, data collection procedure, and analysis procedure (Morse et al., 2002; Shenton, 2004). Although generalizability was not a goal of this study, the in-depth information developed may provide a foundation for future research with diverse populations.

The strategy used to establish dependability was triangulation. The use of the interview protocol, the audio-recorded interviews, and the transcriptions of the interviews provided the path to ensure consistency from one interview to another (Hernández et al., 2003). The consistency confirmed the accuracy of the findings and assured the results were supported by the data collected since the strategy merges information from diverse

sources (Morse et al., 2002; Shenton, 2004).

Confirmability was established using reflexivity. As I analyzed the data, I not only assessed what was being said in the common text but also how my attitude, views, and position influenced the interpretation of the results (Morse et al., 2002; Shenton, 2004). My field notes and journaling were of immense help (Glatthorn & Joyner, 2005; Glicken, 2003).

### **Results**

The findings obtained from the data analysis answer the research question: How are caregivers influenced by the care recipients' physical and psychosocial health conditions and their meaning of care dependence? The seven participants that were interviewed held a positive perception about how the care recipients' health conditions influenced their caregiving. Participant 1 stated:

I will not deny there were moments I wanted to throw the towel. But no, I realized the care recipients depended on me. I prayed to God so he would help me keep moving forward to help my relatives. I wanted to show them my love and affection through my caregiving for they were my family and because there was no one else to care for them.

Participant 2 commented, It is very difficult, but you need to put to work your abilities and strength. Participant 4 added, It depends on how you deal psychologically with the care recipient and manipulate their body. Participant 5 mentioned, You need to educate the care recipient and relatives on what is care dependence because it affects the caregiver's life from all perspectives: physical, emotional, psychological, and spiritual."

Regarding the care dependence meaning, an interesting observation was made by participant 2 who stated:

It is a relationship; an interaction or what people call a bond established with persons who are waiting for you to help, to resolve, and who knows they can ask you for anything since with or without knowing they become part of your life.

This interaction fills your life, your heart, fulfills your day, and/or makes you feel needed.

Participant 1 mentioned, I gave all I had for them to live a while longer. The experience was what satisfied me most and led me to value life more. Participant 4 commented, You need to have compassion and be sympathetic. When they are no longer by, one gets stressed and depressed. Other participants' perspectives were:

This is a tough area. As a daughter, one feels responsible for the care offered, especially in our culture. This speaks about the quality of life and when they are gone, no one is to have has a guilty conscience. (Participant 5)

Caregiving is a tough situation for those helping as for the care recipients who depend on you. On occasions, you do not know what to do or how to do some things due to the lack of information. This may lead to unintended mistakes, and it makes you feel impotent. (Participant 3).

The thematic analysis resulted in five themes which are Human Behavior, Needs, Concerns, Education, and Communication. Table 2 below summarizes the results. After the table, I discuss each theme.

**Table 2***Summary of Results*

Interview Questions	Themes	Codes	Sub-Codes
1,2,3,4, 5,6,7	Human Behavior	Relationships (7)	Emotional (17) Personal (8) Social (9) Spiritual (6)
1,2,3,4,7	Needs	Care (27)	Care Dependence (10) Caregiving Skills (3) Family Needs (5) Financial Costs (1) Safety and Quality of Life (4)
1,5,6	Concerns	Family (6)  Caregivers (23)	Care Responsibilities (5) Safety and Quality of Care (4) Financial Costs (1)  Care Dependence (10) Safety and Quality of Life (4) Change of Environment (2) Caregiving Skills (3) Isolation Risks (1) Support and Assistance (3) Fair Pay (1) Mistreatment/Abuse (2) No Emotional Attachment (2) Compassion and Empathy (6)
6,7	Education	Family Members and Caregivers (2)	Development of Caregiving Skills (1) Communication Strategies (2) Care Dependence (11) Tolerance (2)
2,3	Communication	Family Members and Caregivers (6)	Lack of Understanding (5) Share (9) Changes in Mood (3) Emotional (5) Smooth and Calm (2) Repetitive (3) No Contradictions (2)

**Theme I: Human Behavior**

Human behavior encompasses a variety of physical actions and observable emotions (Anholt & McKay, 2010). It is driven by thoughts and feelings and can reveal attitudes and different behaviors. Human behavior can be influenced by factors such as genetics, social norms, faith, attitudes, and culture.

For this study, human behavior arises from the relationship between caregivers and their care recipients. Help provided is related to activities of daily living and/or instrumental, although help can also be offered for tasks like the ones mentioned by the following participants:

Participant 6 said, I cleaned his skin lesions, and he apologized for what he made me do due to his health condition (morbid fat). I also bathe him and helped with the exercises to strengthen his muscles. Participant 5 commented, While at school and with limited financial resources, I became my mother's physical therapist. I never imagined the chromotherapy could heal a skin lesion she had for eleven years in only ten days. I was very surprised.

Observable emotions can be either positive or negative. Positive emotions relate to satisfaction, empathy, compassion, tolerance, respect, love, and gratitude to mention a few. Negative emotions are associated with anger, frustration, anxiety, and depression, among others. Since caregivers' behaviors are driven by their thoughts, feelings, and perceptions, they can reveal attitudes (Anholt & McKay, 2010). Participant 6 said, Based on your emotional state at the moment is how you will do things. He continued, Caregivers are also human and can have feelings of anger, anxiety, frustration, and



depression. The importance lies in what are you going to do with those feelings.

Teamwork is necessary to obtain either a respite or time for oneself. Participant 2 added,

Caregiving is not just a job but a feeling and if you cannot feel, what you do will not work because you will end up angry, mistreating, and/or abusing seniors, children, or patients. This is a job where you are willing to give, not an obligation. Then, the message to the caregivers is if you feel you are not empathic and/or compassionate, you should seek another job.

Sharing is an essential social skill that helps build healthy and strong relationships (Kjesbo, 2010). It contributes to the wellbeing and happiness of others and helps avoid loneliness. Sharing also offers time for a person to be heard, and to feel at ease and at peace. The literature supports care recipients' changes in behaviors. As participant 2 commented, When my mother is receptive and in a good mood sharing is easy. However, there are days that nothing matters depending on her emotional status. The participant continued saying,

“This is like a seesaw. When she feels angry, weary, or sick and tired of living she does not care about anyone else but herself, this is what I believe. Many times, she accepts situations pretty well, but when feeling nostalgic she is thankful with sadness, pain, and tears. She asks for forgiveness for being foolish, for not being able to understand, and although she is grateful, she did not express her gratitude in a proper way. Then, what can I do, other than embrace her? Yet, there have been days that one would have wanted to shut the door and never come back. So, this is a give and take. We both give each other in diverse ways and at the same

time the situation promotes meaning in our lives.”

Participant 6 also mentioned,

After the bath, we talked for a while or watched tv together because humans need to share and feel loved. Fraternizing is necessary for a person to feel alive, accepted, and to lift his/her spirit instead of becoming a hindrance or a piece of furniture.

### **Theme II: Needs**

Needs are a psychological feature that leads a person to act toward a goal and can give or direct a behavior (Dove, 2015). Needs can be physical (e.g. food or shelter), subjective such as the need to contribute (e.g. give, care, protect, serve others), or for safety (e.g. for security, comfort, consistency). Caregivers' provision of care must include safety as explained by participant 4, Caregivers' way of caring has to do with safety to avoid endangering the care recipient's life.

The care recipient's awareness of their situation besides their cooperation can be of immense help for the caregiver as participant 6 comments, He was conscience he needed the help, and he accepted it. Care recipients need to feel that your caregiving is something you do because you are happy and comfortable helping. It is also important to follow health professionals' advice. Participant 5 also added, Caregivers need other professionals because caregivers are barely heard. They need to: tell how they feel, feel they are cared for, feel they are loved, receive support, and share and learn new behavior techniques.

**Theme III: Concerns**

Concerns refer to a feeling of worry or care about a person or thing leading to anxiety. These relate to aspects of safety, housing, legal documents, the managing of finances, paying for care, and the managing of care, among others. For adult children and relatives growing old is a matter of concern as expressed by participant 2:

“Today we are young, but tomorrow will be old. Who will care for us if we do not care for them? The person I care for has 88 years, disabled with marked physical limitations. It is hard to watch her trying to live and trying to move day by day. Here is where I come in trying to offer some relief, by helping her with the daily tasks, her hygiene, and keeping her company which is of utmost importance for seniors. Seniors need to know they are loved and that someone is there for them.”

With the high cost of living, expensive medications and medical services, small pensions, and lack of government help the biggest concern for caregivers, family, and even the care recipients themselves are the finances. Participant 3 had to deal with her relative's financial costs. She commented, Her health insurance did not help much. On the other hand, based on the complexity of the care offered, participant 4 said, Caregivers are in the need of respect and fair pay.

**Theme IV: Education**

Education and learning are two social and interactive processes (Williams, 2017). From the caring perspective, education implies the acquisition of knowledge, skills, values, beliefs, and habits. Caregivers and their relatives need to learn and keep informed about the recipient's health condition. The information helps in knowing care recipients'

needs, characteristics, and preferences besides the skills which need to be developed. Education also helps in knowing how to manage the different situations encountered, learning communication strategies, behaviors to be expected according to the type of health condition, and the changes needed in the context (if any). Regarding the acquisition of knowledge and skills, participant 5 explained,

“You can care give but you need to teach the recipient to do his/her things (something not done in our culture) or cooperate with the work at home, otherwise, they will not do anything. As they are taught, care recipients feel useful and give you a break. If you teach the recipient to be independent, you will have some freedom. If you always do the whole job, the message is --you are useless and will always depend on me. From an emotional perspective, there can be no complaints because you gave them the wrong instructions. Then, care dependence is either taught or learned. Therefore, you need to educate the care recipient and their relatives on what care dependence is because this affects the caregiver’s life from all perspectives: emotional, psychological, physical, and spiritual.”

### **Theme V: Communication**

Communication helps to build relationships through the sharing of experiences and needs while relating with other human beings. It is important in life because it allows us to express feelings, exchange thoughts, and pass on information. Communication among people allows not only the expression of ideas and feelings (McPheat, 2019) but also contributes to understanding other persons' emotions and thoughts, as the development of affection or hate towards them. This is depicted in participant 1

comment, Communication with my care recipients was a sharing of affection, love, and respect. I spoke to the care recipients in a very plain and calm manner for them to understand and accept the help being offered.

Participant 6 said,

When helping a person, one should feel well with oneself, otherwise the smallest detail will make you angry, aggressive, and lack empathy. Humans need to know their limits to avoid raising their voices or screaming, as to understand that things are a matter of actions and consequences.

### **Summary**

In this chapter, I provided the key findings of the study. The findings obtained from the data analysis helped answer the research question: How are caregivers influenced by the care recipients' physical and psychosocial health conditions and their meaning of care dependence? The findings support that the interviewed participants perceived the care recipients' health conditions negatively affect or influence their caregiving from different perspectives as are emotional, psychological, physical, and spiritual. In addition, care dependence's meaning for each caregiver related to the caregiver's feelings for the care recipient and how they perceived the caring context. I also discussed themes and included phrases from the participants' responses that connected to each theme. The trustworthiness issues were also explained.

In Chapter 5, I will discuss my interpretations of the study's findings. I will also explain the limitations of the study and the recommendations for further research. I will comment on the implications for the practice and its influence on social change.

## Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this generic qualitative study was to explore how caregivers are influenced by the care recipients' physical and psychosocial health conditions and their meaning of care dependence. The current research study was considered after noticing how the changes in longevity have impacted family structure altering seniors' lifestyles. Negatively charged atmospheres between family members favors tension and may lead to conflict (Jesmin et al., 2011) affecting both the caregiver and the recipient. Although caregivers' support is usually welcomed, on occasions their actions or behaviors limit recipients and make them feel helpless, insecure, and even frightened. Situations of this nature lead to believe the assistance or support provided may be damaging (Coudin & Alexopoulos, 2010; AARP, 2015). Caregivers' behaviors nowadays are vital because social norms have changed and values have eroded (Jesmin et al., 2011). Studies suggest the way caregivers experience and organize their caring tasks may not only originate from culture and sociostructural demographics but may also be the expression of individual personality differences (Rohr et al., 2013; Hollis, 2003). With a caregiving industry needing to be regulated (AARP, 2015), it is necessary to understand caregivers' attitudes, actions, and behaviors to not only avoid danger in the caring context and ensure the safety of elders and disabled persons (Schmitt, 2015; AARP, 2015) but most of all to ensure caregivers' wellbeing so they can continue their assistance.

The findings showed that the interviewed participants held a positive perception about how the care recipients' health conditions affect their caregiving and their meaning of the concept of care dependence. Such perceptions, related to the provision of

assistance in diverse ways and for a variety of reasons, are usually rooted in cultural values. Environments and contexts can influence people's views to different degrees, but participants' perceptions or perspectives also vary depending on the way situations are faced and managed. According to the study's findings, caregiving is burdensome and can negatively affect the caregivers' health from different perspectives as emotional, psychological, physical, and spiritual. The findings also revealed that care dependence's specific meaning for each caregiver is based on the caregiver's feelings for the care recipient and their perception of the caring context.

### **Interpretations of the Findings**

The findings of the study were consistent with what previous researchers had found about caregiving assistance. The findings revealed that caregiving is burdensome and can negatively affect the caregivers' health from various perspectives as are emotional, psychological, physical, and spiritual as mentioned by Participant 5. The findings are further discussed in the next sections.

### **Caregiving and Caregivers**

Previous research revealed that caregiving relates to psychosocial support and direct care related to illness and aging, which is provided by an informal caregiver usually in the care recipient's home (Branchet et al., 2018; Eifert et al., 2015; Salazar-Maya et al., 2020; Tavaréz et al., 2020). The care that seeks to alleviate human suffering is guided by motives of respect, love, empathy, and compassion (Erikson, 2002). Care also leads to a dependence relationship reason for which caregivers need to know the recipient's needs, characteristics, and preferences to allow a long-term relationship

influenced by lifestyle, cultural values, interests, spirituality, and face-to-face contact (Crandall, 2014; Lowenstein, 2010; Pharr et al., 2014). Participant 1 relates her despair to the circumstances of living with her relatives. She never gave up willing to show her relatives her love, affection, and respect through her caregiving despite her depression, sadness, and crying. Her feelings for her relatives gave her the strength to continue forward even when being tired or upset.

The informal caregiver, usually a family member (spouses and/or adult children), spends most of the time providing unpaid care, has little or no specific training, and is most likely a female. This caregiver is viewed as the main responsible person for the homecare, the physical and emotional support, the decision-making, the care recipient's health, and who also helps with the financial support (Barbosa et al., 2011; Dixie & Querido, 2020; Eifert et al., 2015; Gans, 2013; Gorawara-Bhat et al., 2019; Ramírez-Perdomo et al., 2018). The findings support the literature because all seven participants in the study were informal caregivers.

Care is an integral aspect of human nature (Ludgren & Berg, 2010). It is influenced by values, motives, beliefs, and culture (Crandall, 2014), and the care recipient's attitude and condition. Therefore, giving or receiving care can have different meanings according to the interpretation and the focus. Shahgholian and Yousefi (2018) mentioned that the word "care" has a variety of meanings like protection, attention, the lookout on, and wellbeing. However, from the care recipient's perspective, the concept emerged in the form of empathy, social support, concern, and companionship. The findings indicated that for seniors, company is of utmost importance to avoid loneliness.



Participants 2 and 6 expressed that care recipients need to share because fraternizing helps a person to feel human, alive, and accepted, which confirms the literature.

The recipient's needs are of two types (Dove, 2015). They are physical like food, shelter, protection, medications, personal hygiene, instrumental, and financial. But can also be subjective such as comfort, safety, love, and sharing to mention a few.

Participants agreed that the needs are of concern because of the high costs of living, expensive medications and health services, the lack of government help, and the small pensions that do not offer a pleasant nor encouraging panorama for caregivers, relatives, and especially care recipients themselves. Findings confirmed the literature with Participant 3 who commented that health insurance does not help much. Although nursing homes are always an alternative, the costs for caring services are usually forbidden and, in many instances, the institution and the care that it offers must be monitored to ensure quality and safety. The findings also supported the literature through Participant 4 who said when the care recipient is in pain, she treats them nicely and gently because the caregivers' way of caring has to do with safety to avoid endangering them.

The literature also supports care recipients' changes in behaviors. Caring for another person requires a constant cognitive, emotional, and physical effort since the distress and/or burden experienced is linked not only to the care recipient's health condition but also to their behavioral problems (Branger et al., 2018; Morrison et al., 2020; Ramírez-Perdomo et al., 2018). The findings support the literature as revealed by Participant 2 explanation regarding her mother's emotional aspect which resembled a

seesaw. She said when my mother is receptive and in a good mood, sharing is easy. However, there were days that nothing mattered depending on how she felt. When she felt angry, weary, or sick and tired of living she did not care about anyone else but herself. Yet, when feeling nostalgic she was thankful with sadness, pain, and tears. She asked for forgiveness for being foolish, and not being able to understand, and although she was grateful for the help, she did not properly express her gratitude. Participant 2 also stated there were days that she would have wanted to shut the door and never come back.

According to Azoir-Hui et al. (2010), improper behaviors may be heightened in situations with disabled persons particularly when the care recipient becomes distressed. The provision of help or assistance depends on how the negative behaviors are attributed. Attributions could lead to positive (pity or sympathy) or negative (anger or disgust) emotions (Azoir-Hui et al., 2010). In situations where attributions favor positive moods, caregivers will be open to providing help but when dealing with negative feelings and problem behaviors (due to a long-standing personality or behavioral pattern), caregivers will be reluctant to assist. Therefore, caregivers' attributions can affect or influence the quality of the relationship with their care recipient (Azoir-Hui et al., 2010). Good relations are of extreme importance, for such reason caregivers need to avoid aggressive behaviors, abuse, mistreatment, and the care recipient's neglect (Carretero & Garcés, 2011). The findings indicate that the caregivers need to be aware that at some point he/she will experience behaviors like anger, depression, and/or anxiety. Participant 6 comments that it is of utmost importance to know what is going to happen with those feelings and most of all how will they be managed. Participant 5 added that caregivers

need to take care of themselves since mood changes might make them aggressive with the care recipient and that is not good.

According to Williams (2017), education and learning are two social and interactive processes that are essential in caregiving because information allows openness and knowledge. Care recipient's needs, characteristics, and preferences can guide toward the awareness of temperaments, motives, intentions, behaviors, reactions to expect, the type of skills to develop, how to effectively communicate, the changes needed in the context, and how to adapt to certain situations, among others. The findings also support that education can help to manage the different situations to be faced in the caring context besides the learning of communication strategies as experienced by Participant 3 who mentioned it was very tough since no one is prepared for this type of situation and what is implied. She had no choice but to take over feeling impotent for not knowing and being able to do more. Knowledge promotes quality of life and safety for both the caregivers and the care recipients.

Communication helps to build relationships through the sharing of experiences and needs while relating with other human beings. It is important in life because it allows to express feelings, exchange thoughts and ideas, and for the passing of information. Communication among people allows not only the expression of ideas and feelings but also contributes to understanding others' emotions and thoughts and the development of affection or hate (McPheat, 2019). The finding supports the literature as explained by Participant 1 who spoke to her relatives in a very plain and calm manner for them to understand and accept the help being offered. She did not contradict them to avoid the

care recipients' anger or arguments because seniors can be willful.

### **Burden-Related Factors and Feelings**

The literature also indicates that to avoid risks related to chronic illness, burnout, and financial challenges, caregivers utilize social support, competencies, networking, problem-solving skills, and positive coping strategies, besides finding meaning and purpose to develop better relationships with the care recipient and to improve the quality of life (Berry et al., 2012; Eifert et al., 2015; Morrison et al., 2020; Tavarez et al., 2020). Identifying factors associated with the caregiver's burden could help with the prevention (Cabral et al., 2013). Among the strategies to prevent burden and exhaustion are rest, psychoeducational interventions, cognitive-behavioral therapy, training, information on how to provide care (Vandepitte et al., 2016), counseling, and personal care services (like home health and adult day care centers). To decrease tension, Eifert et al. (2015) suggested the sharing of the care responsibility or respite. Another finding of the study is explained by Participant 6 who mentions the existence of situations that humans cannot withstand or resists for a long time. Such situations may become a sign of the need for rest. For such reasons alternatives that become important are teamwork, a change of environment, seek for help, or just sitting doing nothing.

### **Care Dependence**

For Piredda et al. (2016), dependence is inherent in humans due to a relational nature, frailty, and bodily vulnerability. Several researchers identified care dependence as a complex phenomenon with multiple meanings (Branchet et al., 2018). According to Ramírez-Perdomo et al. (2018), as aging persons become dependent, they experience

concern, fear, and stress. When care recipients become aware of their bodily changes, they begin to feel useless, vulnerable, powerless, and mistrust their body's capacity, skills, health, and ability to work. Caregivers recognize the fragility to which care recipients are exposed due to their health conditions, but also understand how harsh circumstances can become because dependence leads to anger and stress. Again, the study's findings check the literature. Participant 2 explained about her 88 years old mother who is disabled due to her musculoskeletal condition that led her to an extremely reduced mobility. She continued to say how sad is to watch her mom daily trying to move and live. Seeking to help due to the circumstances, this participant offered care, support and kept her mom company, even though the situation was very frustrating and stressful with many unanswered questions.

While the circumstances refrain the caregiver from abandoning the recipient, the caregiver ends up isolated limiting his/her social life, neglecting his/her health, increasing the homecare, and ending up overloaded (Liljeroos et al., 2014). The caregiver could also experience anxiety, stress, and emotional problems like depression that shows through a variety of symptoms such as the desire to cry, irritability, fatigue, sadness, lack of concentration, sleeping problems, and headaches (Navarro-Sáñdoval et al., 2017; Salazar -Maya et al., 2020). Contrary to the literature, the findings verified by Participant 5, showed care dependence affects/influences the caregiver's life and caregiving from different perspectives like emotional, psychological, physical, and spiritual. Nevertheless, the dyad becomes an important entity by preventing its members from perceiving themselves as a "burden" (Bierhals et al., 2017) using spirituality (Torkenaes et al., 2015)

and religiosity (Nemati et al., 2017; Newberry et al., 2013). The findings verifying the literature relates to Participant 1 whose faith, love, affection, and gratitude led her to help and care give her relatives that totally depended on her for there was no one else to care for them. Therefore, she prayed to God a lot so he would help her keep the strength to help her relatives.

The act of caregiving has a specific meaning for each caregiver, but those meanings are intertwined with the caregiver's perception of the care recipient (Gorawara-Bhat et al., 2019). For such reason care dependence is said to be camouflaged (Strandberg & Jansson, 2003), that is, something is being covered to make it blend in with the surroundings. However, contrary to the literature, findings show that this camouflaged can be inferred from all seven caregiver's feelings for the care recipient besides their perception of the caring context which is gradually internalized. Participant 1 mentioned she wanted to show her relatives her love, affection, and gratitude through her caregiving for they were her family and because there was no one else to care for them. Participant 7 stated that she wanted her son to be happy and to have a life as meaningful as she could make it. Participant 3 said that she felt impotent not being able to help more. Dependence is no longer something to overcome because it can serve as the means through which human growth is possible (Valdes-Stauber et al., 2018). In the past, dependence was considered a distressing experience due to regression and powerlessness (Piredda et al., 2016) and its strong impact on the quality of life (Candela et al., 2020). Nowadays, dependency is viewed as a key characteristic of human beings (Colombetti, 2013). The openness of human beings to those in need relate to humans' innate capacity

to go beyond themselves in helping others, that is, to self-transcend (Frankl, 1985) which as the findings show is what all seven participants have done through their caregiving. For Participant 2 care dependence refers not only to a relationship or interaction, but more so to what people call a “bond” established between the caregiver and the care recipient who is waiting for help and knows that he/she can ask for help knowing or not that he/she will eventually become part of one’s life. Such interaction will either fulfill one’s day or make oneself feel needed. Also, contrary to the literature Participant 5 explained that care recipients need to be taught (something not done in our culture), that is, that within their limits either do their things or cooperate with the work at home, otherwise, they will end up doing nothing. The teaching helps care recipients to feel good, useful, and retain their autonomy. Relatives who usually find themselves lost and/or tend to monopolize the caregiver, need to allow caregivers some freedom and respite. As relatives are taught what to do and how to deal with the caring situations, caregivers gain time for themselves, and stress is reduced. However, care dependence has been a relevant issue in late life because the aging process decreases cognitive, physical, interpersonal, and financial resources. During adulthood, the age at which dependence begins, those with whom older adults come to depend on and feel comfortable being dependent varies widely (Fiori, Consedine & Magai, 2008). Engaging themselves in aspects of dependence has helped older adults reinforce their skills and compensate for the reduction of resources. Then, dependence can be viewed as a limited situation allowing life to be experienced more deeply, by reinterpreting its meaning, value, and envisioning life’s essential dimensions. Dependence is to function as an enzyme, by

catalyzing the reevaluation of small and important beautiful things that went unnoticed in a rushed and healthy life.

Based on culture, it is adult children's responsibility to provide for their parents (Pharr et al., 2014). Because behaviors are driven by thoughts and feelings, they can reveal attitudes (Anholt & McKay, 2010). Positive emotions that are highly desired for caregiving are satisfaction, compassion, tolerance, respect, and love because these help to reach out to care recipients in the establishment of long-lasting relationships. When negative emotions associated with distress, anger, frustration, anxiety, and depression invade the caregiver due to fatigue or unmet expectations the questions to be answered, as Participant 6 comments are, what is to be done with these feelings and how are they to be managed? Participant 6 continues to say, based on the caregiver's emotional state and attitude at the moment is how things will be done. The findings also revealed that caregivers need to be heard. Expressing their feelings provides them relief since the tension and pressure experienced during the service is too much. Participant 5 said that caregivers need other professionals because they are barely heard. They need to tell how they feel, feel they are cared for, feel they are loved, receive support, and share and learn new behavior techniques.

### **The Construction of Meaning**

Humans characterize by relationality. Human beings not only depend on one another, but they also need to stay connected with other humans to be recognized as valuable persons, feel loved, develop their identity, and live a meaningful life (Candela et al., 2020). Meaning and purpose are central to life but more so when caring for someone



with an incurable condition (Cherry et al., 2019). Caring for relatives may lead to experiencing a similar or higher level of distress than that of an ill family member, burden with care efforts and psychological strain throughout the progression of the disease, and experience loss as before grief. Meaning in life refers to the order, coherence, and purpose of one's existence, the pursuit and attainment of goals, and the sense of fulfillment (Reker, 2000). It protects from depression and anxiety (Scheffold et al., 2014), and promotes resilience in a "limit situation" (Valdes-Stauber, 2016). A strong or stable sense of meaning in life could positively influence resilience to protect caregivers against demoralization and balance the sense of impotence (e.g., terminally ill family member), in addition to reducing the sense of guilt due to negative feelings (e.g., helping relieve personal burden) (Valdés-Stauber et al., 2018; Tang et al., 2013). Quinn et al. (2013) identified two sources of meaning which could motivate caregivers to care: first, the sense of the continuity of the dyad, and second, the caring process itself. However, what remains unclear is why some caregivers derive meaning from caregiving while others do not. Findings verify the literature through Participant 7 who comments she wanted her son to be happy and to have a life as meaningful as she could make it. Participant 2 added that the caregiving gave her not only a feeling of accomplishment as a family member but also gave meaning to her life through those whom she cared for and loved.

### **The Caregiver's Identity Theory**

The Caregiver's Identity Theory (Montgomery & Kosloski, 2009) was used to guide the study. The theory posits that caregivers must change their behaviors to align

with their identity standard, change their *identity* standard, or change their self-appraisal or perception for it to be compatible with the circumstances. Identity which influences behavior (Eifert et al., 2015) is complex, socially constructed, and develops from the interaction of a person's psychobiological aspects and the social context (Kroger, 2006). The identity structure helps regulate and govern people's lives by “providing a sense of self-continuity and a frame of reference for making decisions, problem-solving, interpreting experience, and self-relevant information” (Berzonsky et al., 2011, p.295). Then, people get to know themselves by interacting with others and understanding how others see them (Erikson, 1968). In addition, identity is not fixed for it continues to develop and evolve (Berzonsky et al., 2011), to promote evaluation, reconfiguration, and change (Cross et al., 1991). As Banaji and Prentice (1995) suggested, identity changes result from major changes in the role and situational demands. Erikson (1968, 1980) and Deaux (1993) mentioned that identity formation has two dimensions: (a) the self, which is reflexive and includes the traits and behaviors, and (b) the role which occurs if acknowledged and supported by others.

The findings supported the theory since all seven participants were family caregivers. In their caring context, all seven participants established a care dependence relationship with their care recipients leading them to transitions in identity due to their care recipients' needs that kept increasing (in quantity and intensity) based on their health conditions and situational demands. Factors associated with these seven caregivers' distress and burden (Cabral et al., 2013) related to their sociodemographic characteristics (age, gender, education, and experience), the care recipient's type of

needs, the duration of care, degree of kinship, and their psychological health (Dixie & Querido, 2020; Zhu & Jiang, 2018).

### **Limitations of the Study**

One limitation relates to the participants in this study who shared their experiences with this female researcher that viewed and interpreted their stories through her lens. This could have influenced the sharing or elaboration of the details regarding their experiences as well as the perceived meanings (Creswell, 2009; Mertens, 2005).

Another limitation is the sample size. The sample interviewed was constituted of seven caregivers for a generic qualitative approach which suggests the use of a small sample to allow for the development of an in-depth analysis (Creswell, 2009; Mertens, 2005). Although generalizability was not a goal of this qualitative research study, the in-depth information developed is transferable and provides a foundation for future research with other populations (Creswell, 2009; Mertens, 2005).

### **Recommendations**

This research study can be expanded to other cities within the mainland where the target population is larger. The use of another qualitative method like a case study could prove to be more informative and potentially increase education awareness regarding the different ways to approach the recipients and strategies to manage their limitations or disability. Further research could also provide suggestions as well as methods to address, monitor, and manage conflictive situations among family members.

Participant 5 recommended some things caregivers should do. First, caregivers should research to be able to help the care recipient with his/her needs, especially with

medications and therapy. Second, caregivers are not to complain but to determine the strategies to resolve a situation. Third, caregivers should treat their care recipients (when possible) by taking them out to have fun and enjoy themselves with them. Fourth, caregivers need to take care of themselves, otherwise, they will experience mood changes and become aggressive with the care recipient. Fifth, caregivers need to be good observers because observations allow researching and assessing situations and circumstances faced in the caring context for the caregivers to grow and to adequately react and respond. Sixth, the caregiving experience is negative because caregivers neglect themselves while caring for the recipient. Seventh, it is important that caregivers know how to paraphrase and verify when communicating with the care recipient for a better understanding. Eighth, when care dependence is either taught or learned, the caregiver will feel better and different. Ninth, caregivers need other professionals because caregivers are barely heard. They need to tell how they feel, feel they are cared for, feel they are loved, receive support, and share and learn new behavior techniques.

It is through communication, another important aspect of care, that those in the context can express their needs, request help, learn and train, share with others, enjoy happy moments, and resolve the many emerging concerns related to care like finances. Observations and communication will also help when getting support.

### **Implications for Social Change**

Although care dependence still refers to a subjective necessity for support compensating a self-care deficit (Boggatz et al., 2007), its views have changed. Nowadays, dependency is viewed as a key characteristic of human beings whose

openness to those in need goes beyond themselves as they transcend seeking to help others. Human service professionals, community members, and relatives need to understand the new caring perspectives and the changes that take place. The findings from this study may be used to promote awareness about the dependence relationship which is a mutual emotional response of empathy between the caregiver and the recipient. Human service professionals could use the findings from the study for the provision of support programs, training courses, and services for caregivers and their relatives for the maintenance of better relationships, conflict resolution, improving communication skills, and quality care among others to help caregivers succeed. Human service professionals should prepare and present the programs and services for caregivers from a practical perspective because by presenting how the program or service benefits may be a better option for a caregiver to consider. As an agent of social change, I intend to share the findings of this study by presenting the results at conferences and workshops.

### **Conclusions**

Care dependence refers to a subjective necessity for support compensating for a self-care deficit (Boggatz et al., 2007). In the past, dependence was considered a distressing experience because it affected caregivers from various perspectives, and it was due to the senior's regression and powerlessness, besides its strong impact on the quality of life. However, dependence is not something to overcome because it can serve as the means through which human growth is possible. Nowadays, dependency is viewed as a key characteristic of human beings. The openness of humans toward those in need relate to humans' innate capacity to go beyond themselves or transcend for helping

others. Care dependence is a relationship that establishes when the recipient decides and accepts his/her situation. The way care is performed depends on cultural values, motivations, beliefs, and the recipient's attitudes and/or health conditions. The care dependence relationship seeks to alleviate human suffering through a mutually emotional response of empathy between the caregiver and the recipient.

## References

- American Association of Retired People (2015, March). Outrage! <http://aarp.org/bulletin>
- American Geriatrics Society. (n.d.). *Aging in the know: Mental retardation*.  
[http://www.healthinaging.org/agingintheknow/chapters\\_print\\_ch\\_trial.asp?ch=37](http://www.healthinaging.org/agingintheknow/chapters_print_ch_trial.asp?ch=37)
- Banaji, M. R. & Prentice, D. A. (1995). The self in social contexts. *Annual Review of Psychology*, 45, 297-332.
- Barbosa, A., Figueiredo, D., Sousa, L. & Demain, S. (2011). Coping with the caregiving role: Differences between primary and secondary caregivers of dependent elderly people. *Aging and Mental Health*, 15 (4), 490-499.  
<https://doi.org/0.1080/13607863.2010.543660>
- Bennett, T. & Gaines, J. (2010). Believing what you hear: The impact of aging stereotypes upon the old. *Educational Gerontology*, 36, 435-445.  
<https://doi.org/10.1080/03601270903212336>
- Berry, J. W., Elliot T. R., Grant, J.S., Edwards, G. & Fine, P. R. (2012). Does problem solving training for family caregivers benefit their care recipients with severe disabilities? A latent growth model of the project CLUES randomized clinical trial. *Rehabilitation Psychology*, 57 (2), 98-112. <https://doi.org/10.1037/a0028229>
- Berzonsky, M. D., Ciecuch, J., Duriez, B. & Soenens, B. (2011). The how and what of identity formation: Associations between identity styles and value orientations. *Personal Individual Differences*, 50, 295-299.  
<https://doi.org/10.1111/j.1365-2648.2007.04456.x>
- Bierhals, C. (2017). Needs of family caregivers in home care for older adults. *Revista*

*Latinoamericana de Enfermagem*, 2 (e2870), 46-5.

<https://doi.org/10.1590/1518-8345.1511.2870>

Bogatz, T., Dijkstra, A., Lohrmann, C. & Dassen, T. (2007). The meaning of care dependency as shared by caregivers and care recipients: A concept analysis.

*Journal of Advanced Nursing*, 60 (5), 561-569.

<https://doi.org/10.1111/j.1365-2648.2007.04456.x>

Bouget, D., Spasova, S. & Vanhercke, B. (2016). *Work-life balance measures for persons of working age with dependent relatives in Europe: A study of national policies*.

Brussels, Belgium: European Commission. Directorate-General for Employment, Social Affairs, and Inclusion. European Social Policy Network.

Branchet, B., Monfort, E., Poulet, C. & Weil, G. (2018). A triadic approach to health and dependence in aging adults: incongruence in perception. *Quality of Life Research*,

27, 3047-3055. <https://doi.org/10.1007/s11136-018-1950-0>

Branger, C., Enright, J., O'Connell, M. E. & Morgan, D. G. (2018). Variance in caregiver burden predicted by patient behaviors versus neuropsychological profile. *Applied Neuropsychology: Adult*,

25(5), 441-447.

<https://doi.org/10.1080/2327/9095.2017.1323754>

Brank, E. M. & Wylie, L.E. (201). Differing perspectives on older adult caregiving.

*Journal of Applied Gerontology*, 35 (7), 698-720.

<https://doi.org/10.1177/0733464813517506>

Cabral, M., Ferreira, P., Silva, P., Jerónimo, P. & Marques, T. (2013). *Proceso de envejecimiento en Portugal: Usos de tiempo, redes sociales y condiciones de vida*.



Francisco Manuel dos Santos. <http://hdl.handle.net/10451/24456>

- Candela, M.L., Piredda, M., Marchetti, A., Facchinetti, G., Iacorossi, L., Capuzzo, M. T., Mecugni, D., Rasero, L., Matrese, M. & Grazzi De Marinis, M. (2020). Finding meaning in life: An exploration on the experiences with dependence on care of patients with advanced cancer and nurses caring for them. *Supportive Care in Cancer*, 28, 4493-4499. <https://doi.org/10.1007/s00520-020-05300-8>
- Carretero, S & Garcés, J. (2011). Psychological interventions to fight against the burden of the informal caregivers. *European Psychiatry*, 26, 1-7. [https://doi.org/10.1016/S0924-9338\(11\)72878-4](https://doi.org/10.1016/S0924-9338(11)72878-4)
- Carretero, S., Stewart, J. & Centeno, C. (2015). Information and communication technologies for informal careers and paid assistants: Benefits from micro-, meso- and macro-levels. *European Journal of Ageing*, 12(2), 163–73. <https://doi.org/10.1007/s10433-015-0333-4>
- Cherry, M. G., Ablet, J. R., Dickson, J. M., Powell, D., Sikdar, S. & Salmon, P. (2019). A qualitative study of the processes by which carers of people with dementia derive meaning from caring. *Aging & Mental Health*, 23(1), 69-76.
- Colombetti, E. (2013). The shared dependency. *Medicine*, 21(2), 24-29.
- Cho, E. (2007). A proposed theoretical framework addressing the effects of informal caregivers on health-related outcomes of elderly recipient in-home health care. *Asian Nursing Research*, 1(1), 23-34.
- Connell, C. M., & Gibson, G. (1997). Racial, ethnic, and cultural differences in dementia caregiving: review and analysis. *Gerontologist*, 37 (3), 355-64.

- Coyle, N. & Sculco, L. (2004). Expressed desire for hastened death in seven patients living with advanced cancer: A phenomenologic inquiry. *Oncology Nursing Forum*, 31(4), 699–709.
- Crandall-Mills, D. L. (2014). Exploring the lived experiences of older father caregivers of adult children with intellectual disabilities. (Doctoral Dissertation, Capella University, 2014). ProQuest Dissertations Publishing, 3609710.
- Creswell, J. (2018). *Research design: Qualitative, quantitative, and mixed methods approach*. Sage.
- Cross, S.P. & Markus, H. (1991). Possible selves across the life span. *Human Development*, 34 (4), 230-255.
- Deaux, K. (1993). Reconstructing social identity. *Personality and Social Psychology Bulletin*, 19, 4-12.
- DeLiema, M., Gassoumis, Z. Homeier, D. & Wilber, K. (2012). Determining prevalence and correlates of elders' abuse using promoters: Low-income immigrant Latinos report high rates of abuse and neglect. *The American Geriatrics Society*, 60 (7), 1333-1339. <http://doi.org/10.1111/j.1532-5415.2012.04025.x>
- DePoy, E. & Gilson, S.F. (2012). *Human behavior theory and applications: A critical thinking approach*. Sage.
- Dilworth-Anderson, P., Williams, I. C., and Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *Gerontologist*, 42 (2), 237-72.
- Dixie, M. A. & Querido, A. I. (2020). Informal caregiver of dependent person in self-

care: burden-related factors. *Revista de Enfermagem Referencia*, 3, 1-8.

<https://doi.org/10.12707/RV20013>

Dube, S. & Choyal, T. (2012). Leisure: Effect on healthy ageing. *Indian Journal of Gerontology*, 26 (3), 414-423.

Eagly, A. (2009). The his and hers of prosocial behavior: An examination of the social psychology of gender. *American Psychologist*, 64(8), 642-658.

Eifert, E. K., Adams, R., Dudley, W. & Perko, M. (2015). Family caregiver identity development: A literature review. *American Journal of Health Education*, 46 (6), 357-367. <http://www.shapeamerica.org>

Erikson, E. (1968). *Identity: Youth and crisis*. Norton.

Erikson, E. (1980). *Identity and the life cycle*. Norton.

Erikson, K. (2002). Caring science in a new key. *Nursing Science*, 15, 61-65.

Frankl, V. (1966). Self-transcendence as a human phenomenon, *Journal of Human Psychology*, 6 (2), 97-106.

Frankl, V. (1985). *Man's search for meaning: An introduction to logotherapy* (74<sup>th</sup> ed). Simon & Schuster.

Friedmann, M. L. & Buckwalter, K. C. (2014). Family caregiver role and burden related to gender and family relationships. *Journal of Family Nursing*, 20, 313-336.

Fusch, P.I. & Ness, L. R. (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20 (9), 408-1416.

<https://www.nova.edu/ssss/QR/QR20/9/fucschl.pdf>

Gans, D. (2013). Guest editor comments, introduction to the special issue. *Journal of*

*Comparative Family Studies*, 44 (4), 415-424.

Gibson-Hunt, G. & Reinhard, S. (2016). The impact of America's changing family upon federal and state caregiving policy. *Generations*, 39 (4), 73-79.

Giorgi, A. (1992). Description versus interpretation: Competing alternative strategies for qualitative research. *Journal of Phenomenological Psychology*, 23, 119-135.

Glaser, J. & Laudel, G. (2013). Life with and without coding: Two methods for early-stage data analysis in qualitative research aiming at casual explanations. *Social Research*, 14 (2), 1- 28.

<http://www.qualitativeresearch.net/index.php/fqs/article/view/1886/3528>

Glathorn, A. & Joyner, R. (2005). *Writing the winning thesis or dissertation*. Corwin Press.

Glicken, M.D. (2003). *Social research: A simple guide*. Allyn and Bacon.

Gorawara-Bhat, R., Graupner, J., Molony, J. & Thompson, K. (2019). Informal caregiving in a medically underserved community: Challenges, construction of meaning, and the caregiver-recipient dyad. *Open Nursing*, 5, 1-12.

<https://doi.org/10.1177/2377960819844670>

Griffith, D. A., Morris, E. S. & Thakkar, V. (2016). Spatial autocorrelation and qualitative sampling: The case of snowball sampling designs. *Annals of the American Association of Geographers*, 106 (4), 773-787.

<https://doi.org/10.1080/24694452.2016.1164580>

Gringeri, C., Barush, A. & Cambron, C. (2013). Epistemology in qualitative social work research: A review of published articles. *National Association of Social Workers*,

- 37 (1), 55-63. <https://doi.org/10.1093/swr/svs032>
- 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. <https://doi.org/10.1177/1525822X05279903>
- Haley, W. E. (1995). Psychological, social, and health impact of caregiving: A comparison of Black and White dementia family caregivers and non-caregivers. *Psychology and Aging*, 10 (4), 540-552.
- Henskens, M., Nauta, I. M., Katja, T. D. & Maarten, V, M. (2019). Predictors of care dependency in nursing home residents with moderate to severe dementia: a cross-sectional study. *International Journal of Nursing Studies*, 92, 47-54. <https://doi.org/10.1016/j.ijnurstu.2018.12.005>
- Hernández, R., Fernández, C. & Baptista, P. (2003). *Research methodology*. McGraw Hill.
- Hughes, N., Locock, L. & Ziebland, S. (2013). Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. *Social Science and Medicine*, 96, 78-85. <http://doi.org/10.1016/j.socscimed.2013.07.023>
- Hunt, G., Levine, C., & Naiditch, L. (2005). *Young caregivers in the U.S.: Findings from a national survey*. National Alliance for Caregiving, in collaboration with the United Hospital Fund. <http://222.uhfnyc.org>.
- Illés, S. (2013). Spaces and places of successful ageing. *Analele Universității din Oradea-Seria Geografie*, 109 -17.
- Jesmin, S., Amin, I. & Ingman, S. (2011). Aging and caregiving crisis in the low- and

- middle-income societies. *Indian Journal of Gerontology*, 25 (3), 309-328.
- Juntunen, K., Salminen, A. L., Tormakangas, T., Tillman, P., Leinonen, K. & Nikander, R. (2018). Perceived burden among spouse, adult children, and parent caregivers. *Journal of Advanced Nursing*, 74, 2340-2350. <https://doi.org/10.1111/jan.13733>
- Kahlke, R. M. (2014). Generic Qualitative Approaches: Pitfalls and Benefits of Methodological Mixology. *International Journal of Qualitative Methods*, 13, 37-49. <https://doi.org/10.1177/1609406914013001119>
- Khalaila, R. & Litwin, H. (2011). Does filial piety decrease depression among family caregivers? *Aging and Mental Health*, 15 (6), 679-686. <https://doi.org/10.1111/j.13652648.2010.05606.x>
- Kirsi, T., Hervonen, A. & Jylha, M. (2000). "A man's gotta do what a man's gotta do": Husbands as caregivers to their demented wives, a discourse analytic approach. *Journal of Aging Stud.*, 14 (2), 153-169.
- Kjesbo, R. R. (2010). Sharing an important social skill! <http://www.handyhanhouts.com>
- Kroger J. (2006). Identity in late adulthood. In Kroger J. (Ed), *Identity Development: Adolescence Through Adulthood (2nd ed., pp 191-216)*. Sage.
- Lacey, A. & Luff, D. (2009). Qualitative data analysis. *National Institute for Research Health*. <http://www.rds-yh.nihr.ac.uk/wp-content/uploads2013/05/9-Qualitative>
- Laverty S. (2003). Hermeneutic Phenomenology and Phenomenology: a comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2 (3), 1-15.
- Leedy, P. & Ormrod, J. (2010). *Practical research: Planning and design* (9<sup>th</sup> ed.).

Prentice-Hall.

- Levine, C., Hunt, G. G., Halper, D., Hart, A. Y., Lautz, J., & Gould, D. A. (2005). Young adult caregivers: A first look at an unstudied population. *American Journal of Public Health, 95*, 2071–2075.
- Liljeroos, M., Agren, S., Jaarsma & Strömberg, A. (2014). Perceived caring needs in patient-partner dyads affected by heart failure: A qualitative study. *Journal of Clinical Nursing, 23* (19-20), 2928-2938. <https://doi.org/10.1111/jocn.12588>
- Lincoln, Y.S. & Guba, E.G. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N.K. Denzin & Y.S. Lincoln (Eds.), *Handbook of qualitative research* (2<sup>nd</sup> ed., pp. 163-188). Sage.
- Lloyd, J., Bond, F. W. & Flaxman, P. E. (2013). The value of psychological flexibility: Examining psychological mechanisms underpinning a cognitive behavioral therapy intervention for burnout. *Work and Stress, 27*, 181-199.
- Lowenstein, A. (2010). Caregiving and elder abuse and neglect-Developing a new conceptual perspective. *Aging International, 35*, 215-227.  
<https://doi.org/10.1007/s12126-010-9068.x>
- Lu, N., Liu, J., Wang, F. & Lou, V. (2017) Caring for disabled older adults with musculoskeletal conditions: A transactional model of caregivers' burden, coping strategies, and depressive symptoms. *Archives of Gerontology and Geriatric, 69*, (1). <http://doi.org/10.1016/j.rchger.2018.1100>
- McPhearson, C. J., Wilson, K. G. & Murray, M. A. (2007). Feeling like a burden to others: A systematic review focusing on the end of life. *Palliative Medicine, 21*

(2), 115-128.

McPheat, S. (2014). Effective communication skills. MTD Training.

<http://www.m-t-d.co.uk>

Marcia, J. E. (1966). Development and validation of ego-identity status. *Journal of Personality and Social Psychology*, 3, 551–558.

Marcia, J. E. (1993). The ego identity status approach to ego identity. In J. E. Marcia, A. S. Waterman, D. R. Matteson, S. L. Archer, & J. L. Orlofsky (Eds.), *Ego identity: A handbook for psychosocial research* (pp. 3–41). Springer-Verlag.

McPhearson, C. J., Wilson, K. G. & Murray, M. A. (2007). Feeling like a burden to others: A systematic review focusing on the end of life. *Palliative Medicine*, 21 (2), 115-128.

Mak, Y. Y. W. & Elwyn, G. (2005). Voices of the terminally ill: Uncovering the meaning of desire for euthanasia. *Palliative Medicine*, 19 (1), 343–350.

Maguire, M. & Delahunt, B. (2017). Doing a Thematic Analysis: A Practical, Step-by-Step Guide for Learning and Teaching Scholars. *AISHE, J* (3), 3351-33514.

Maldonado, L. (2015). Latinas' intergenerational caregiving: An integrative review of the literature. *Journal of Transcultural Nursing*, 1-9.

<https://doi.org/10.1177/1043659615623329>

Mendez, F. R. (2013). Active ageing: A right or a duty? *Health Sociology Review*, 22 (2), 174-185.

Merriam, S. (2002). *Qualitative research in practice*. Jossey-Bass.

Mertens, D. (2005). *Research and evaluation in education and psychology: Integrating*



- diversity with quantitative, qualitative, and mixed methods* (2nd ed.). Sage.
- Miles, M.B. & Huberman, A.M. (1994). *Qualitative data analysis* (2<sup>nd</sup> ed). Sage.
- Miller, K. I., Shoemaker, M. M., Willyard, J. & Addison, P. (2008). Providing care for elderly parents: A structuration approach to family caregiver identity. *Journal of Family Communication*, 8, 19-43.
- Mitroff & Bonoma (1978). *Evaluation Quarterly*, 2 (2), 235–260.
- Montgomery, R., & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. *Journal of the American Society on Aging*, 33 (1), 47-52. <https://doi.org/10.1017/S1478951517000220>
- Moore, H. & Gillespie, A. (2014). The caregiving bind: Concealing the demands of informal care can undermine the caregiving identity. *Social Science and Medicine*, 116, 102-109.
- Morrison, B., Phillips, B. N., Jones, J. E., Przybelski, R. & Garret, H. (2020). The impact of risk and resistance factors on quality of life in caregivers of individuals with dementia. *Clinical Gerontologist*, 43 (5), 585-597. <https://doi.org/10.1080/07317115.2019.1572039>
- Morse, J. M. (1994). Designing qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative inquiry* (p. 220-235). Sage Publications.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K. & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1 (2), 13-22. <https://doi.org/10.1080/07317115.2019.1572039>

- Navarro-Sandoval, C., Uriostegui-Espíritu, L. C., Delgado-Quiñonez, E. G. & Sahagún-Cuevas, M. N. (2017). Depresión y sobrecarga en cuidadores primarios de pacientes geriátricos con dependencia física de la UMF 171. *Revista Médica del Instituto Mexicano del Seguro Social*, 55 (1), 25-31.
- Nemati, S., Rassouli, M., Mahnaz, D., Pilkhani, C. & Reza-Baghestani, A. (2017). The spiritual challenges faced by family caregivers of patients with cancer: A qualitative study. *Holistic Nursing Practice*, 31 (2), 110-117.  
<https://doi.org/10.1097/HNP0000000000000198>
- Nissim, R., Gagliese, L. & Rodin, G. (2009). The desire for hastened death in individuals with advanced cancer: A longitudinal qualitative study. *Social Science and Medicine*, 69 (2), 165–171.
- Newberry, A. (2013). Exploring spirituality in family caregivers of patients with primary malignant brain tumors across the disease trajectory. *Oncology Nursing Forum*, 40 (3), E1195. <https://doi.org/10.1188/13.ONF.E119-E125>
- Newman B. & Newman, P.R. (2008). *Development through life: A psychosocial approach*. Wadsworth.
- Paoletti, I. & Carvalho, M. I. (2012). Ageing, poverty, and social services in Portugal: The importance of quality services. *Indian Journal of Gerontology*, 26 (3), 396-413.
- Patton, M. Q. (2015). *Qualitative research and evaluation methods*. Sage Publications LTD.
- Penhale, B. (2010). Responding and interviewing in elder abuse and neglect. *Ageing*

*International*, 35, 235-252. <https://doi.org/10.1007/s12126-010-9065-0>

Percy, W. H., Kostere, K. & Kostere, S. (2015). Generic qualitative research in psychology. *The Qualitative Report*, 20 (2), 76-85.

<https://www.nova.edu/ssss/QR/QR20/9/percy5.pdf>

Pharr, J., Dodge Francis, C., Terry, C., & Clark, M. (2014). Culture, caregiving, and health: Exploring the influence of culture on family caregiver experiences. *ISRN Public Health*, 1-8. <https://doi.org/10.1155/2014/689826>

Piredda, M., Bartiromo, C., Capuzzo, M. T., Matarese, M. & De Marini, M. G. (2016). Nursing care dependence in the experiences of advanced cancer inpatients.

*European Journal of Oncology Nursing*, 20, 125-132.

<https://doi.org/10.1016/j.ejon.2015.07.002>

Piredda, M., Candela, M. L., Mastroianni, C., Marchetti, A., D'Angelo, D., Lusignani, M., De Marinis, M. G. & Matarese, M. (2020). "Beyond the boundaries of care dependence" A phenomenological study of the experience of palliative care nurses. *Cancer Nurses*, 43 (4), 331-337.

<https://doi.org/10.1097/NCC0000000000000701>

Pope, N. (2013). Views on aging: How caring for an aging parent influences adult daughter's perspectives on later life. *Journal of Adult Dev*, 20, 46-56.

<https://doi.org/10.1007/s10804-013-9155-9>

Popek, V. & Höning, K. (2015). Cancer and family: Tasks and stress of relatives, *Der Nervenarzt*, 86 (3), 268-270.

Quinn, C., Clare, L. & Woods, R. (2013). Balancing needs: The role of motivations,

meanings, and relationships dynamics in the experience of informal caregivers of people with dementia. *Dementia*, 2, 1-18.

Ramírez-Perdomo, C. A., Chacón-Cuellar, E. & Perdomo-Romero, A. Y. (2018).

Enfrentar la dureza de la enfermedad crónica, retos de la diada: cuidador/persona cuidada. *Cultura de los Cuidados*, 22 (52), 46-57.

<https://doi.org/10.14198/cuid.2018.52.04>

Reker, G. T. (2000). Theoretical perspectives, dimensions, and measurement of existential meaning. *In exploring existential meaning: Optimizing human development across the life span* (Reker & Chamberlain, Eds, pp 39-55). Sage Publications.

Rodriguez-Prat, A., Balaguer, A., Crespo, I. & Monforte-Royo, C. (2018). Feeling like a burden to others and the wish to hasten death in patients advanced illness: A systematic review. *Bioethics*, 33, 411-420. <https://doi.org/10.1111/bioe.12562>

Roth, D. L., Fredman, L. & Haley, W. E. (2015). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist*, 55, 309-319. <https://doi.org/10.1093/geront/gnu177>

Salazar-Maya, A. M., Cardozo-García, Y. & Escobar-Ciro, C. L. (2020). Carga de cuidado de los cuidadores familiares y nivel de dependencia de su familiar. *Investigación en Enfermería: Imagen y Desarrollo*, 22, 1-11.

<https://doi.org/10.11144/Javeriana.ie22.cccf>

Sánchez, L. M. & Carrillo, G. (2017). Competency for homecare of that dyad person with cancer in chemotherapy and his caregiver family. *Psicooncología*, 14 (1), 137-48.

<http://doi.org/10.5209/PSIC.55817>.

- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing and Health*, 23, 334-340.
- Savundranayagam, M. Y. & Montgomery, R. J. V. (2010). Impact of role discrepancies on caregiver burden among spouses. *Research on Aging*, 32, 175-199.
- Schimtt, R. (2015). The stranger in your home. AARP. <https://aarp.org/bulletin>
- Scheffold, K., Mehnert, A. & Müller, V (2014). Sources of meaning in cancer patients: Influences of global meaning, anxiety, and depression in a longitudinal study. *European Journal of Cancer Care*, 23 (4), 472-480.
- Shahgolian, N. & Yusefi, H. (2018). The lived experiences of patients undergoing hemodialysis with the concept of care: a phenomenological study. *BMC Nephrology*, 1-7. <https://doi.org/10.1186/s12882-018-1138-4>
- Sharma-Bhattarai, L. (2013). Reviving the family model of care: Can it be a panacea for the new century? *Indian Journal of Gerontology*, 27 (1), 202-218.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22 (2), 63-75.  
<https://doi.org/10.3233/EFI-2004-22201>
- Shifren, K. (Ed) (2009). *How caregiving affects development: Psychological implications for the child, adolescent, and adult caregivers*. APA.
- Shifren, K. (2017). *Caregiving identity and flexibility. Identity flexibility during adulthood: Perspectives on adult development* (J. Sinnott, Ed, pp. 1-28). Springer.
- Smith-Carrier, T., Pham T., Akhtar, S., Seddon, G., Nowaczynski, M. & Sinha, S. K.

(2018). 'It's not just the word care, it's the meaning of the word...(they) actually care': Caregivers' perceptions of home-based primary care in Toronto, Ontario.

*Ageing & Society*, 2019-2040. <https://doi.org/10.1017/S0144686X1700040X>

Stiel, S., Pestinger, M., Moser, A., Widdershoven, G., Lüke, U., Meyer, G. & Radbruch,

L. (2010). The use of grounded theory in palliative care: Methodological challenges and strategies. *Journal of Palliative Medicine*, 13 (8), 997–1003.

<https://doi.org/10.1007/978-3-319-55658-1.18>

Skaiff, M. M., & Pearlin, L. I. (1992). Caregiving: Role engulfment and the loss of self.

*The Gerontologist*, 32, 656-664.

Strandberg, G. & Jansson, L. (2003). The meaning of dependency on care as narrated by

nurses. *Scandinavian Journal of Caring Sciences*, 17, 84-91.

Tang, S. T., Cheng, C. C. & Lee, K. C. (2013). Mediating effects of sense of coherence

on family caregivers' depressive distress while caring for terminally ill cancer patients. *Cancer Nursing*, 36 (6), E25-E33.

Tavares, M.L.O., Pimenta, A.M., García-Vivar, C., Beinrer, A. & Montenegro, L.C.

(2020). Relationship between the level of care dependency and quality of life of family caregivers of care-dependence patients. *Journal of Family Nursing*, 26 (1), 65-76.

The National Alliance for Caregiving and AARP (2009), Caregiving in the U.S. The

National Alliance for Caregiving.

The National Alliance for Caregiving and the AARP Public Policy Institute (2015).

Caregiving in the U.S. 2015. <http://www.caregiving.org/caregiving2015/>

- Torskenæs, K. (2015). Nurses' and caregivers' definition of spirituality from the Christian perspective: A comparative study between Malta and Norway. *Journal of Nursing Management*, 23 (1), 39-53. <https://doi.org/10.1111/jonm.12080>
- Troll, L. E. & Skaff, M.M. (1997). Perceived continuity of self in very old age. *Psychology and Aging*, 12, 162-169.
- Turner, J.H. & Stets, J.E. (2006). Sociological theories of human emotions. *Annual Review of Sociology*, 32, 25-52. <https://doi.org/10.1146/annurev.soc.32.061604.123130>
- Valdes-Strauber, J. (2016). Man at the frontier of his being: Scope of the concept of “limit situation” in psychiatry and psychotherapy following Jaspers' existential ontology. *Fortschritte der Neurologie-Psychiatrie*, 84 (1), 19-27.
- Valdes-Strauber, J., Lemaczyc, R. & Kilian, R. (2018). Sources of meaning in family caregivers of terminally ill patients supported by a palliative nursing care team: A naturalistic three-month cohort study. *Palliative and Supportive Care*, 16, 246-259. <https://doi.org/10.1017/S1478951517000220>
- Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., Faes, K. & Annemans, L. (2016). Effectiveness of supporting informal caregivers of people with dementia: A systematic review of randomized and non-randomized controlled trials. *Journal of Alzheimer's Disease*, 52 (3), 929-65. <https://doi.org/10.3233/JAD-151011>
- Whitbourne, S. K. (1986). *The me I know: A study of adult identity*. Springer-Verlag
- Wiles, J. (2011). Reflections on being a recipient of care: vexing the concept of

vulnerability. *Social & Cultural Geography*, 12 (6), 573-588.

<https://doi.org/10.1080/14649365.2011.601237>

Williams, M.K. (2017). John Dewey in the 21<sup>st</sup> century. *Journal of Inquiry and Action in Education*, 9 (1), 91-102.

World Health Organization (2013). *Active ageing, a policy framework*.

<http://activeageing@who.int>

Yin, R. K. (2012). *Application of case study research* (3rd ed.). Sage Publications.

Zehner, V., & Walker, A. (2014). A comparison of physical health outcomes for caregiving parents and caregiving adult children. *Family Relations*, 63, 163-17.

<https://doi.org/10.1111/fare.12046>

Zhu, W & Jiang, Y. (2018). A meta-analytic study of predictors for informal caregiver burden in patients with stroke. *Journal of Stroke and Cerebrovascular Diseases*, 27 (12), 3636-3646. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2018.08.037>



