

DISSERTATION

LIFE AFTER CAREGIVING: UNDERSTANDING EVERYDAY RESILIENCE IN THE
CONTEXT OF THE BEREAVEMENT PHASE OF THE CAREGIVER JOURNEY

Submitted by

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ABSTRACT

LIFE AFTER CAREGIVING: UNDERSTANDING EVERYDAY RESILIENCE IN THE CONTEXT OF THE BEREAVEMENT PHASE OF THE CAREGIVER JOURNEY

Dementia is a progressive illness that results in cognitive decline for aging adults requiring increased assistance with everyday life as symptoms worsen over time. An illness that is found largely in older adults, dementia rates are rising with the aging population. Dementia often is considered one of the most challenging illnesses for caregivers, given its progressive nature and the individual's subsequent, increased, and complex care needs. Much of the daily care for individuals with dementia is carried out by family members including spouses. Due to the ever-changing complexity of dementia care, spousal dementia caregivers (SDCs) are at an increased risk for negative health and well-being impacts, compared to their non-caregiving cohorts. The caregiving trajectory for SDCs inevitably includes the loss of the spouse, which ushers in one of the most difficult and disruptive role transitions experienced during the life course. The caregiver journey, however, does not necessarily end when the individual with dementia dies, but begins the final bereavement phase of the caregiver journey.

This dissertation examines the experience of SDCs and the role of resilience during the bereavement phase of the caregiver journey. I conducted a phenomenological study to increase our understanding of the everyday lived experience of resilience for SDCs during the bereavement phase of the caregiver journey. I also completed a phenomenographical study to capture how SDCs conceptualized their experience during the bereavement phase of the caregiver journey. I offer key takeaways from the studies, then discuss my research approach and

recommendations for future research and practice addressing resilience and dementia caregiving.

I end this dissertation by situating my work within Occupational Science and Rehabilitation Science.

Keywords: aging, older adults, dementia, caregiving, resilience, occupational therapy

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CHAPTER 1: INTRODUCTION

Dementia is a progressive illness that results in cognitive decline in older adults requiring increased assistance with care as the symptoms worsen over time. According to the Alzheimer's Association (2020), 16 million Americans provided an estimated 18.5 billion hours of unpaid care to family and friends with dementia in 2019, and these numbers are expected to continue to increase with the aging population. This unpaid, or informal, caregiving is primarily provided by family and friends who often lack formal training in meeting the caregiving needs of a person with dementia (Dooley & Hinojosa, 2004). Dementia often is considered one of the most challenging illnesses for caregivers given its progressive nature and the subsequent increased care needs of those experiencing it (Chiao et al., 2015). Due to the nature of the care required for an individual with dementia, caregivers are at an increased risk of caregiver burden, negative physical and mental health impacts, and financial hardship (Brodaty & Donkin, 2009). This caregiver strain results in \$11.8 billion in additional personal healthcare costs for primary caregivers of individuals with dementia compared to their non-caregiving cohort (Alzheimer's Association, 2020). Primary caregivers are "individuals who self-identify as having primary responsibility for providing care" to the care recipient (Schulz & Eden, 2016, p. 50). Schulz and Beach (1999) reported that spousal caregivers who report strain related to dementia caregiving face a mortality risk that is 63% higher than their non-caregiving cohort. In terms of resilience in the context of aging and caregiving, severity of decreased physical and mental health are considered risk-, or vulnerability, factors that may hinder positive adaptive coping responses to life challenges (Hildon et al., 2008; Hutcheon & Lashewicz, 2014). Additional risk factors for negative health impacts associated with dementia caregiving include decreased well-being,

decreased life satisfaction, isolation and decreased social connection, and financial hardship (Brown & Bond, 2016; DiGiacomo et al., 2013). These components of the caregiving trajectory can continue to have significant impacts on caregivers after the death of their spouse. These cumulative health and well-being impacts also have the potential to influence the everyday experience of bereavement for spousal caregivers.

For spousal dementia caregivers (SDCs), bereavement can be conceptualized as the condition of having experienced the loss of their spouse (Hoppes & Segal, 2010). Loss from the death of a spouse has been described as one of the most disruptive and difficult role transitions that one may encounter during their life course (Feldman, 1999). As Peacock, Hammond-Collins, and Forbes (2014) indicate, the caregiving journey does not end when the individual with dementia dies but, rather, ushers in the final stage of the process of caregiving. Due to the high level of risk factors associated with caregiving, it increasingly is likely that caregivers of individuals with dementia are entering the bereavement phase already compromised by elements of their caregiver experience (Schulz et al., 2008). In addition, caregivers will be experiencing grief and mourning related to the death of their spouse, including the adjustment to new roles and routines following the loss of their role as an active caregiver (Hagman, 2001; Hoppes & Segal, 2010; McIntyre & Howie, 2002). The caregiver journey, including bereavement, constitutes a complex, lengthy and significant life experience for SDCs that impacts many, if not all, facets of their lives.

Understanding these significant life experiences of caregivers may be of particular importance for occupational therapists. In order truly to support older adults, including SDCs, occupational therapists need to address the loss, which is integral to providing holistic, client-centered occupational therapy (OT) services (Hoppes & Segal, 2010). A lack of OT research

literature on this topic, however, points to a failure by researchers to address substantially and integrate concepts related to occupational adaptation to life challenges and transitions, such as bereavement (Hoppes & Segal, 2010; McIntyre & Howie, 2002). This lack of research has real life implications for occupational therapy practice. Given the increased risks of negative health impacts for SDCs coupled with increased risk for comorbid health conditions, there is an increased likelihood that SDCs will be seen for occupational therapy services throughout their caregiver journey (Schulz & Beach, 1999). OTs who are not sensitive to the processes related to caregiving, loss, and bereavement are at risk of being unable to provide appropriate holistic, client-centered occupational therapy care for these individuals. Research that leads OTs to an increased understanding of protective factors that promote and facilitate resilience, as well as the mitigating vulnerability factors that put caregivers at an increased risk for negative health impacts during the caregiver journey, including bereavement, is essential for informed practice. This increased understanding of resilience can provide practitioners with valuable awareness and insights into the experiences of spousal caregivers of individuals with dementia. Additionally, OTs with increased understanding of resilience in the context of bereavement, will be able to provide valuable approaches that deliberately embed and promote components of resilience into practice to enhance client health, wellness, and quality of life for both current and future performance and participation in everyday life. The aim of this dissertation is to better understand resilience within the context of the bereavement phase of the caregiver journey.

Research Need

The topic of resilience in the context of aging is gaining increasing attention across multiple disciplines. Previously, research on resilience primarily focused on development in early childhood and adolescence (Hildon et al., 2008; Masten, 2001; Ong et al., 2009). Resilience

research initially also focused on trait-based definitions of resilience that centered on innate attributes of an individual, so that researchers could use those definitions to determine whether the individual is resilient in the face of traumatic experiences (Jacelon, 1997; Richardson, 2002). Eventually, researchers began to study the need to broaden the conceptualization of resilience to include additional populations not addressed in earlier resilience work, such as older adults and caregivers, as well as the need to extend beyond individual trait-based definitions of resilience, by also looking at contextual factors that impact resilience (Bolton et al., 2016; Richardson, 2002). Subsequently, research on resilience is expanding in current literature to represent varied experiences among diverse populations, and across the life span. SDCs are one of the populations underrepresented in previous resilience research. This gap is particularly noticeable when one seeks to find research literature that has examined the bereavement phase of the caregiver journey. The work of this dissertation addresses this research gap by sharing the voices of spousal caregivers as they describe their experiences during bereavement, and by expanding on current conceptualizations of resilience with these individuals.

Conceptualizations of resilience within current research include: an individual's ability to bounce back or cope successfully despite substantial adversity (Earvolino-Ramirez, 2007; Rutter, 1985); an individual's capacity to maintain stability, endure, and recover in light of negative life events (Martin et al., 2015; McMurray et al., 2008; Waugh et al., 2008); an individual's capacity to navigate adversity in a manner that protects health, well-being, and life satisfaction (Manning, 2013; Reich et al., 2010); and a dynamic process in which an individual who experiences adversity, thereafter is able to reintegrate and flourish despite the experience (Bolton et al., 2016). Resilience in the literature generally refers to a pattern of functioning indicative of positive adaptation in the context of significant risk or adversity (Ong et al., 2009). For the

purposes of this study, resilience was conceptualized as the dynamic process of an individual's ability to navigate and overcome life challenges. This definition builds on elements of the above definitions to expand the resiliency conceptualization, and thus allow the inclusion of older adults and SDCs to engage fully in the process of resilience (Bolton et al., 2016; Manning, 2013; Reich et al., 2010).

Personal Positioning & Philosophical Paradigm

Every individual brings their own unique ideas, perspectives, and experiences to any given task. These personal considerations, in turn, influence each new experience. As a researcher, I value the understanding that comes from capturing and describing the lived experience from the individual's first-hand perspective of their everyday life. Every person has a story to tell or an experience to share. Older adults, including spousal caregivers of individuals with dementia, have a right to be included in the research that strives to represent them and to have their voices heard and valued as a critical piece to understanding their lived experience. People matter and people's stories matter.

I believe understanding about the lived experience can best be obtained through the interactive process of knowledge construction. I also believe knowledge is subjective, contextual, socially constructed, and fluid. Knowledge is constructed through the transactional elements of one's experience. Our knowledge cannot be separated from our subjective self. Knowledge influences our experiences and our experiences, in turn, influence our knowledge. This knowledge is always socially and culturally situated. There is a continual process of knowledge construction that has the potential to change as a result of shifts in personal and/or contextual factors. All the SDCs that participated in my research had something beneficial to offer and played a key role in constructing this knowledge. This knowledge was co-constructed, by myself

and my research participants, through an iterative process of sharing both knowledge and experiences. Knowledge also was co-constructed by combining current understandings found in the literature with SDCs' personal understandings of their lived experiences of resilience within the context of bereavement. This process constructed a new knowledge within my area of research shaped by our mutual understandings, contexts, discussions, and reflections. Each part of the research process has the potential to shift understanding and build new knowledge.

Given these considerations, the methods that guided my research are strongly situated within naturalistic approaches and qualitative methods. I feel that the best way to capture the essence of an experience is through the personal accounts of the individuals who are living through the type of experience you are researching. One way to capture this is through the use of face-to-face interviews that include open-ended questions related to the area of research. Interviews have the potential to allow research participants opportunities to reflect on their experience and then share the stories and reflections of their experiences with the researcher. The researcher, in turn, may have the opportunity to build on information provided by the individuals to simultaneously guide the current interview and build additional questions or avenues of inquiry for future consideration. This process is interactive and greatly influences the resulting information provided by the interviews. The key to this process requires the researcher to be careful and deliberate in capturing the experience of the research participants as well as to represent this experience accurately and meaningfully in one's research. It also is essential that the researcher carefully selects study methods that will address accurately and guide the researcher to find answers to her/his questions.

As I developed the questions for these studies, it was important for me to choose a paradigm to guide my research that aligns with the above considerations. Paradigmatic

considerations of your research should support your personal considerations to produce research that represents your values and core beliefs about the world. Based on my personal considerations listed above, I believe my research is most comfortably situated within a constructivist paradigm (Lincoln et al., 2011).

Constructivism provides a strong paradigmatic fit for capturing the “experience” of spousal caregivers of individuals with dementia following the loss of their spouse on multiple levels. According to Lincoln et al. (2011), the ontology of constructivism assumes a pluralistic and relatively constructed nature of reality. In terms of social constructionism, “there can never be definitive answers to questions about the nature of human and social phenomenon” (Burr, 2015, p. 223). Individuals experience the world around them from a variety of perspectives which creates multiple realities. My research acknowledges the existence of multiple socially-constructed realities, and in turn attempts to capture an understanding of the experience of resilience from a group of individuals, spousal caregivers of individuals with dementia, a group minimally represented in the resilience literature. Knowledge is considered subjective, constructed, contextual, and transactional within the constructivist paradigm (Lincoln et al., 2011). Knowledge is one of the many socially constructed and coordinated activities carried out by individuals in their attempts to create understanding and meaning in their worlds (Schwandt, 1998). I value the constructed nature of knowledge and am interested in using the process of knowledge construction to gain a deeper understanding of the lived experience of resilience in the context of bereavement for spousal caregivers of individuals with dementia.

Methodologically, constructivism seeks to understand and interpret experience using the hermeneutic cycle where action leads to the collection of data which, in turn, leads to the interpretation of data, which then initiates action based on these data (Lincoln et al., 2011).

Qualitative approaches are used generally within a constructivist paradigm with the intent of capturing accurate representations of the lived experience that emerge from the interaction and dialogue between the researcher and the research participants as they collaboratively construct meaning (Angen, 2000). The overarching inquiry aim, both of my research and of constructivism, is to understand, interpret, and describe others' lived experiences.

Theoretical Framework

Resilience is multifaceted and the result of a dynamic process that varies across the life span (Bolton et al., 2016). While resilience initially was considered an innate personality trait threatened by the inherently negative aspects of aging, current conceptualizations of resilience include processes and resources that are available at all stages of life, including the potential for resilience to develop over time (Cicchetti & Garmezy, 1993; Luthar et al., 2000; Seccombe, 2002; Wild et al., 2013). The life course perspective provides a back-drop to understanding resilience in the context of aging, through the consideration of the acquisition and interaction of variables throughout the life span that can either facilitate or hinder resilience (Elder, 2001). Developmental psychology strongly influences resilience research within the social sciences, which is represented by its focus on resilience in relation to risks that pose a threat to normal development (Masten, 2001; Masten et al., 1999; Wild et al., 2013). In terms of resilience in the context of aging, “older adults have accumulated life experiences that serve as a potential reservoir of protective factors to be used to successfully cope with the adversities experienced in later stages of life” (Martin et al., 2015, p. 33). As Halfon & Hochstein (2002) indicate, it is critical for researchers to consider the cumulative risks, protective factors, numerous interacting influences across changing contexts, and the impact of biological, psychological, cultural, historical, and sociopolitical issues in the life trajectories of individuals as they age and the

subsequent potential effects on resilience. Ecological models of resilience (Aldwin & Igarashi, 2012) and elements of narrative theory (Richardson, 2000) are highlighted in this examination of the life course perspective as it relates to resilience in the context of aging.

Ecological models focus on the nuances of resilience with particular interest in the ecological characteristics situated in the interactions of the person and the social environment (Harvey, 2007; Lenette et al., 2012). An ecological perspective proposes that “the transactional process between the nested levels of individual, family, community, and culture contributes to both assets and vulnerabilities in resilience” (Aldwin & Igarashi, 2012, p.119). Ungar (2004) suggests constructivist perspectives of resilience are well-aligned with the ecological models since resilience is viewed as an outcome of the negotiations between individuals and their environment. Additionally, the ecological model embraces the idea of multiple pathways to resilience (Aldwin & Igarashi, 2012). This model allows for the construction and consideration of positive outcomes and resilience in the context of aging. The process of aging can be a time of immense changes and monumental transitions leading to transactional periods in which older adults are susceptible to vulnerabilities. Aging, however, also can be a time for positive adaptations, including opportunities for growth and wisdom creation (Aldwin & Igarashi, 2012; Gluck et al., 2005; Masten & Obradovic, 2008). Similar discussions additionally are evident in the use of narrative theory to examine transitions during the course of aging.

Narrative theory brings the addition of the concept of the life story-line to the life course approach, and contends that “people tend to formulate their lives into a coherent and meaningful story” (Leonard & Burns, 2006, p. 28) reflecting their sense of identity (McAdams, 1989). Constructing a narrative identity, or life story, is a life-long endeavor (McAdams, 2001; Randall et al., 2015). Therapeutic life review further involves the goal of finding meaning through one’s

life experiences across the life span, and how we “story” (Kenyon et al., 2011) our life is critical for our identity construction and the subsequent process of meaning-making (Randall & Kenyon, 2001). Older adults “story” their lives around significant events over their lifetime and participate in an active, reflexive process that enables opportunities for resilience through learning, growth, and wisdom (Gattuso, 2003; Nelson-Becker, 2013). Describing turning points is one of the ways older adults reflect on important events in their life story.

Turning points are “significant life events, experiences, and realizations” and “constitute a fundamental shift in meaning, purpose, or direction of a person’s life” (King et al., 2003, p. 186). Turning points can be positive or negative (Turner & Avison, 1992), cumulative episodes or sudden, single events (King et al., 2003); gradual understandings or sudden illuminations; and personal, subjective experiences or situational occasions (Denzin, 1989). Reflecting on turning points in the context of their life story allows older adults a chance to construct and re/interpret past events in order to clarify the meaning of these experiences, preserve their sense of identity, and increase awareness of personal growth in light of these experiences (Hildon et al., 2008; Leonard & Burns, 2006). This self-reflective process can prove essential for older adults in developing and maintaining resilience during the aging process (Hildon et al., 2008). Narrative approaches, including reflecting on turning points, provide a valuable way for researchers to understand, or “story,” resilience in the context of aging.

Structure of the Dissertation

The format for this dissertation contains two manuscripts that will be submitted for publication in peer-reviewed journals. The first of these studies, presented in Chapter 2, takes a phenomenological look at the everyday lived experience of resilience during the bereavement phase of the caregiver journey. The second study, presented in Chapter 3, uses

phenomenography to examine the different ways in which spousal caregivers of individuals with dementia conceptualize the experience of the bereavement phase of the caregiver journey. The final chapter provides an overall summary of how the findings of my studies relate to one another and the implications for occupational therapy practice. This chapter also situates my research within occupational science and rehabilitation science, as well as provides a plan for future work and dissemination of findings.

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CHAPTER 2: STUDY 1

Resilience Rooted in Everyday Experience: A Phenomenological Study of Spousal Dementia Caregivers During the Bereavement Phase of the Caregiver Journey

Dementia is a progressive illness that results in cognitive decline for the older adult population requiring increased assistance with care as the symptoms progress. According to the Alzheimer's Association (2020), 16 million Americans provided an estimated 18.5 billion hours of unpaid care to family and friends with dementia in 2019 and these numbers are expected to continue to increase with the aging population. Dementia is considered one of the most challenging illnesses for caregivers, given its progressive nature and the subsequent increased care needs of those who are experiencing it (Chiao et al., 2015). Due to the demanding and persistent nature of the care required for an individual with dementia, caregivers are at an increased risk of burden, negative physical and mental health impacts, and financial hardship (Brodaty & Donkin, 2009). Caregiver tendencies to prioritize the care of their loved one over their own health and well-being needs, coupled with decreased communication of those needs, leads to decreased social connection and increased isolation (DiGiacomo et al., 2013). This period can be considered as the active caregiving phase of the caregiver journey. The cumulative effects of chronic stress during dementia caregiving impact physical and psychosocial well-being and persist through the transition out of the caregiver role (Brown & Bond, 2016). The risk factors associated with active caregiving can continue on during bereavement to impact the everyday lives of caregivers, even after their loved one has passed away.

Bereavement can be conceptualized as the "condition of having experienced a loss" (Hoppes & Segal, 2010, p. 134). One of the most disruptive and difficult role transitions one may

face during their life course results from the loss of a spouse due to their death (Field et al., 1999). Field et al. describes how the death of a spouse necessitates a reimagining of future life plans including constructing a new identity separate from their spouse. As Peacock et al. (2014) point out, the caregiving journey does not end when the individual with dementia dies but, rather, ushers in the final stage of the process of caregiving. This final stage can be considered the bereavement phase of the caregiver journey.

Due to negative health and well-being impacts associated with active caregiving such as chronic stress and decreased mental health, it is important to consider how elements of the active caregiving experience may continue to impact everyday life for caregivers during the bereavement phase (Schulz et al., 2008). Bereavement is experienced on a day-to-day basis as active caregiving roles and routines are lost and reorganized during the bereavement phase. Additionally, caregivers will be experiencing grief and mourning related to the death of their spouse that demands adaptation and a “reorganization of the survivor’s sense of self” (Hagman, 2001, p. 19). Spousal dementia caregivers (SDCs) will be adjusting to both the loss of their spousal role and the loss of their active caregiver role (Hoppes & Segal, 2010). As Lloyd et al. (2016) notes, for many SDCs, the caregiver role gave their lives significant purpose and meaning. Engagement in everyday life during bereavement is directly impacted by this adjustment to new roles and routines (McIntyre & Howie, 2002). The caregiver journey, including bereavement, constitutes a complex and lengthy series of significant life transitions for SDCs that requires continually adaptation to everyday life challenges. Exploring the resilience of SDCs offers a tool to examine adaptation in everyday life and adjustment to new roles during bereavement. The bereavement phase of the caregiver journey provides the backdrop for our examination of resilience in the context of caregiving.

What is resilience? Understandings and definitions of resilience have evolved over time. Initially, research on resilience focused primarily on development in early childhood and adolescence (Hildon et al., 2008; Masten, 2001; Ong et al., 2009). Resilience research previously focused on trait-based definitions of resilience that centered on innate attributes of an individual and thus determine whether they are resilient in the face of traumatic experiences (Jacelon, 1997; Richardson, 2002). Conceptualizations of resilience within current research include: an individual's ability to bounce back or cope successfully despite substantial adversity (Earvolino-Ramirez, 2007; Rutter, 1985); an individual's capacity to maintain stability, endure, and recover in light of negative life events (Martin et al., 2015; McMurray et al., 2008; Waugh et al., 2008); an individual's capacity to navigate adversity in a manner that protects health, well-being, and life satisfaction (Manning et al., 2016; Reich et al., 2010); and a dynamic process in which an individual who experiences adversity, thereafter is able to reintegrate and flourish despite the experience (Bolton et al., 2016). These understandings shift our view of resilience towards a pattern of functioning indicative of positive adaptation in the context of significant risk or adversity (Ong et al., 2009). These understandings of resilience provide a foundational perspective for framing resilience within the context of the caregiver journey. For SDCs, the caregiver experience, including the eventual death of their spouse, constitutes a significant adverse life event requiring adaptation and adjustment in everyday life to promote health and well-being during bereavement.

Literature focusing on the resilience of dementia caregivers is growing in descriptions of the supports and challenges to resilience during the active phase of the caregiver journey. Caregivers identify patience, flexibility, acceptance, social support, dementia resources, respite, and development of coping skills as instrumental in their ability to navigate the challenges of

caregiving (O'Dwyer et al., 2017). Active caregivers recognize access to social supports from friends and family as well as participation in community supports, such as caregiver support groups where caregivers are able to share their experience and knowledge with other caregivers, as essential to their ongoing resilience (Donnellan et al., 2015).

Literature addressing the bereavement as a part of the caregiver journey is beginning to take shape but is still limited in its analysis. Peacock et al. (2014) extends the discussion of the caregiver journey into bereavement through caregiver descriptions of dementia caregiving including end of life and grief in bereavement. Challenging aspects of active caregiving, such as feelings of loss and guilt, continued to impact the bereavement experience and a variety of supports are needed to meet the unique needs of caregivers during bereavement including care for chronic health conditions and psychosocial support for the grief process (Holtslander et al., 2017). The research team of Peacock et al. (2016) focused on factors that facilitated the bereavement process for spousal dementia caregivers and identified reclaiming self as a key element in navigating bereavement. They found that reclaiming self was facilitated through positive understandings of their spouse's death, positive self-narratives, maintaining a connection to spouse, social support, and staying active.

For the purposes of this study, resilience was conceptualized as the dynamic process of an individual's ability to navigate and overcome life challenges. Viewing resilience as a process allows for multiple avenues to achieve resilience and acknowledges that resilience can change over time based on contextual elements of the experience (MacLeod et al., 2016). Resilience and elements of everyday life such as activities, roles, and relationships are woven together continually to influence and change the fabric of older adults' everyday contexts, creating experiences of varying resilience during the process of aging. For many older adults, these

everyday contexts of life will include the experiences of caregiving. If occupational therapists are going to address the growing health needs of these older adults effectively, an enhanced understanding of dementia caregiving, including the bereavement phase of the caregiver journey, is essential in providing holistic and informed supports and services throughout the entire caregiver journey.

If everyday occupations support well-being during the active caregiving phase (Hasselkus & Murray, 2007), then perhaps this is also an avenue for resilience during the bereavement phase. Current literature has yet to connect elements of resilience and occupation in everyday experience within the context of the bereavement phase of the caregiver journey. This study frames our examination of these questions within the everydayness of resilience that centers on the day-to-day pathways that influence the everyday experience of resilience (Lenette et al., 2012). This study aims to identify, describe, and illustrate the nature of resilience in everyday experience for SDCs during bereavement. We sought to answer how SDCs experience resilience during the bereavement phase of the caregiver journey and what role occupation in everyday experience plays in their resilience.

Methods

Research design. We used a phenomenological approach for this study. Phenomenology allowed us to understand the essence of resilience for SDCs through a first-person account of their lived experience (Creswell & Poth, 2018). It also allowed us to highlight the voices of SDCs as we focused on capturing and understanding the everyday lived experience of resilience for SDCs during the bereavement phase of the caregiver journey.

Participants. Ten women, ages 62-85 years, participated in this study. (See Table 1 for participant characteristics.) Eight of these women lived in Northern Colorado, one lived in

central Colorado, and one lived in New Jersey. To participate in this study, each participant needed to have been a spousal caregiver to someone with dementia who had passed away at least six months prior to participation in the study. This minimal six month post-spousal death timeframe for participant recruitment was employed by the researcher, in order that the caregivers would have had a good amount of time to process and reflect on the loss of their loved ones (Bentley & O’Conner, 2015; Hovland-Scafe & Kramer, 2017). The first author conducted purposive criterion sampling (Patton, 1990) to recruit participants that fit our study criteria and supported the objectives of the study. Women and men from across the county were recruited to participate in the study. The first author emailed representatives from local, state, and national organizations specializing in dementia services and provided a short summary of the study for them to post online and send electronically to potential participants. One participant was recruited through a local dementia organization in Northern Colorado and two participants joined the study after being contacted by family members who worked with the first author in a professional capacity. Seven of the ten participants were recruited through snowball sampling (Patton, 1990) wherein SDCs already participating in the study reached out to other SDCs they knew that might be interested in sharing their experience.

This study was interrupted by the COVID-19 pandemic. COVID-19 is a highly contagious and potentially life-threatening disease discovered in 2019 that caused a world-wide pandemic resulting in recommendations to physically isolate from others (WHO, 2020). The pandemic slowed recruitment efforts by temporarily halting this research project and restarting the project among uncertainties related to guidelines around safe return to research activities. We adjusted to social distancing guidelines by moving all interviews to a phone or virtual platform. Recruitment efforts continued to be impacted by the psychosocial impacts of the pandemic

coupled with the nature of the topic of bereavement. Some potential participants ultimately decided that they just didn't have the emotional capacity to participate in the study.

Ethical considerations. Ethical approval was obtained through the IRB process at Colorado State University, #19-9322H. Prior to their inclusion in the study, potential participants took part in a consent process in which each participant read and signed a consent form, which was approved by the Human Research Committee at Colorado State University. The consent form included a brief overview of the study and interview process, the overall objectives of the study, the expectations for anyone who participated in the study, as well as risks that might be pertinent to the study. All participants were reminded verbally of confidentiality and their right to terminate participation in the study at any time during the research process.

Data collection. The first author conducted semi-structured interviews with open-ended questions to capture the experience of caregiving. The nature of the interview questions allowed participants to share their own experiences in a way that featured their unique perspectives and insights into their experiences. (Please see Table 2.2 for examples of the interview questions.) Each participant engaged in two in-depth interviews, which lasted, on average, 45-75 minutes. The first interview focused on the participant's active caregiving experience into the end-of-life transition. This first interview also allowed an opportunity for the researcher to build rapport with the caregiver before specifically addressing bereavement. The second interview continued the discussion by focusing the questions on the bereavement phase of the caregiver journey. Participating caregivers reported demographic data about themselves and their spouse by completing a caregiver questionnaire (See Table 2.1 for the summary of these data).

Table 2.1

Participant Characteristics

Participant	Spouse Diagnosis	Age	Years Married	Caregiver Age at Diagnosis	Spouse Age at Diagnosis	Spouse Age at Death	Years Spouse was Diagnosed	Years of Active Caregiving	Years Since Death of Spouse
Emily	Dementia	62	26	45	53	66	13	13	4
Marie	Lewy Body Dementia	67	20	60	60	64	4	5	3
Sherry	Progressive Supranuclear Palsy	81	53	74	74	80	6	6	1
Nancy	Vascular Dementia	78	39	66	77	83	6	4	6
Susan	Alzheimer's	67	48	62	67	71	4	4	1
Brenda	Parkinson's with Dementia	83	58	63	62	79	17	5	3
Anna	Alzheimer's	85	58	79	79	85	6	5	1
Jill	Frontotemporal Dementia	72	8	62	62	69	7	5	3
Dawn	Mild Cognitive Impairment	62	31	52	60	66	6	6	4
Betty	Lewy Body Dementia	65	Separated	61	58	61	3	5	1

Table 2.2

Examples of Interview Questions

Tell me about your caregiver experience. What was helpful to you during caregiving? What did you find challenging during caregiving?
Tell me about your life after your spouse passed away. What was helpful to you during this time? What did you find challenging during this time?
Do you still consider yourself a caregiver? - Why or why not?
Do you think that the time after your spouse passed away is still part of the caregiver journey? - Why or why not?

The data collection process for this study was completed in two un-planned phases. The first three participants completed both of their interviews prior to the emergence of the 2020 COVID-19 pandemic. These participants chose the location of their interviews resulting in face-to-face interviews at either a public meeting space or the participant's home. The remaining seven participants completed their interviews virtually using Zoom®, an online video conferencing platform, due to the COVID-19 pandemic. The first three pairs of interviews were audio recorded using a portable digital voice recorder while the last seven pairs of interviews were recorded through the virtual Zoom® platform. All interviews were transcribed verbatim.

Data analysis. A small data analysis team consisted of the first author, a second researcher, and a research assistant. Prior to transcript analysis the first step in data analysis was *familiarization* with the data, during which the first author/interviewer listened to each audio recording to gain a general sense of the interview and became familiar with the data (Braun & Clarke, 2006). The interviewer then listened to each interview for a second time while taking notes of things that stood out to her during the interview. These notes were used by the first

author to generate initial codes and preliminary categories as well as provide content to review for member checks at the beginning of each SDC's second interviews. Member checking provides an opportunity for participants to be a part of the research process by providing feedback and verifying the researcher's interpretations of their words (Savin-Baden & Major, 2013). The first author and research assistant then read the transcripts independently to enhance familiarization and initiate the second step in our data analysis, *open coding*. Open coding involved the first author and research assistant separately assigning descriptive codes to chunks of the interview transcripts (Savin-Baden & Major, 2013). These initial steps began the process of immersing the authors in the data.

The next step involved independent and manual *axial coding* to begin making connections between the initial codes (Savin-Baden & Major, 2013). The research team then collectively *categorized* the codes based on the patterns emerging from the data (Savin-Baden & Major, 2013). Up to this point, manual data analysis allowed researchers to work independently of one another to decrease the potential influence the researchers might have on one another during the coding process. The author then transferred all interview transcripts and categorized codes to a qualitative data management software, NVivo®. All subsequent data analysis for this study occurred in NVivo®. The research team used continual data analysis to establish and refine the categories. The categories then were *converted* into themes that identified the dominant and unifying ideas that emerged from the data (Savin-Baden & Major, 2013). The final themes represent the core features of the phenomenon of resilience for spousal dementia caregivers in this study.

Issues of trustworthiness. The research team addressed data trustworthiness in multiple ways. We used reflexivity and the bracketing of our previous experiences with regards to

caregiving and the phenomenon of resilience (Creswell & Poth, 2018). This was particularly important for the first author/interviewer who has worked in the dementia caregiving community for over a decade and had previous ties to many of the participants in this study through that community work. We used purposive criterion sampling (Patton, 1990) in an attempt to adequately represent the experience of resilience for spousal caregivers of individuals with dementia during the bereavement phase of the caregiver journey. The first author conducted a formal member check at the beginning of each second interview and informal reviews at the end of each interview. This allowed the interviewer and participant the opportunity to jointly review and discuss emerging findings and interpretations of the interview content (Savin-Baden & Major, 2013). We used annotations, memoing, and journaling to provide an audit trail that chronicled the research process and enhanced continuity throughout the study (Birks et al., 2008). This process included decisions related to the evolution of codes, themes, and interpretations. The research team performed initial coding of the transcripts and the preliminary categorization of codes independently before collaborating to produce higher level codes, categorizations, and themes. The research team also included an outside coder (the research assistant), who was unfamiliar with the study prior to involvement. The second researcher served as a peer reviewer to provide an additional outside check of codes and categories. These last two strategies served to increase quality through the triangulation of analysts (Patton, 1990; Savin-Baden & Major, 2013).

Findings

A key feature that emerged from the interviews was that stories of resilience for these SDCs was rooted in their everyday experiences. While they acknowledged fluctuations in their everyday resilience, all caregivers reported feeling overall resilient as they reflected on their

caregiver journey, including bereavement. During their discussions of the bereavement phase of the caregiver journey, all the caregivers expressed concepts related to resilience in ways that linked those concepts closely to ordinary aspects of their everyday lives. The aspects of everyday experience most prevalent in our findings were activities, roles, and relationships. As a result, two themes emerged: (1) Challenges to resilience and (2) Supports to resilience. The following findings related to our themes are structured in a way that highlights the voices of SDCs. (Please see Table 2.3 for an outline of the findings of this study.)

Table 2.3

Outline of Study Findings

Theme	Subthemes
Challenges to Resilience	Being alone Change in everyday activities The grief process
Supports to Resilience	Connections Connections to self Connections to others Connections to community Engagement in activities Meaningful activities Learning and growing Having purpose and meaning Meaning-making Personal perspectives and attitudes Honoring the memory of their spouse Expressions of gratitude

Challenges to resilience. When asked about what they found challenging during the bereavement phase of the caregiver journey, SDCs spoke about elements of bereavement that they found difficult to navigate as they moved forward after the death of their spouse. They shared stories of their day-to-day lives to illustrate the things they struggled with during bereavement. SDCs also expressed challenges in terms of having a hard time coping with key features of the bereavement phase such as being alone, changes in everyday activities, and the grief process itself.

Being alone. “What has changed the most? The loneliness” (Anna). Being alone was reported as one of the biggest challenges for SDCs during bereavement. Caregivers talked about struggling with loneliness following the loss of their husband. They also spoke about missing their “companion” (Brenda) or their “best friend” (Jill).

I think-it's been a couple years, but it's the loneliness. It's the, so, who am I planning vacations with? What do I plan next? What does my life look like?... but there's that, right, people don't get the loneliness part of it. (Betty)

But there's something I want to say. Nobody, nothing takes the place of your husband. You know, everyone says "oh yeah, you're lucky, you have a big family." Yeah, well they don't sleep with me at night...that person that is with you...That loves you best of all. (Nancy)

For many of these caregivers, the death of their spouse left them in an empty house and, for some, living alone for the first time in their lives.

The other thing was I have never lived alone...I went to college, had roommates...came to Colorado, had roommates. Got married, had a roommate. Had kids, had a house full. I'd never been alone. And it took me a long time to be able to sleep. It's been three years, and I'm just getting where I fall asleep a little easier at night. Most nights. Some nights, I still have problems. (Sherry)

Change in everyday activities. Changes in both the activities SDCs engaged in and how they engaged in those activities challenged resilience by requiring continuous acceptance and adjustment throughout bereavement. Change in routines was immediately felt by caregivers who had structured their days around the care of their spouse. Several of the SDCs reflected on their daily routines of visiting their spouse in the facility before their death and how it took time to not feel like they had somewhere to be during the time they would normally visit their spouse in the facility.

One of the biggest things I notice is that I kept wanting to go visit him [at the long-term care facility], and it's like...Okay I have to go visit. And it's like, no, I don't have to go visit. I don't have to make sure that this happened or that happened. (Marie)

And after he passed, I didn't know what to do with myself at 4:30 in the afternoon...And it was hard to - to break out of that routine. It took me probably a month or better to not look at the clock and go, "Oh, I need to leave, I need to get there." And that was really hard. Because it's very depressing. (Susan)

Changes to roles and relationships further challenged caregiver resilience and caused many caregivers to reflect on their sense of identity. As Nancy noted, "everything changes...I'm not good with change." SDCs often reflected on their identity in relation to their everyday activities and how the caregiver role had provided structure and purpose to their daily life.

I used to be someone who met friends once a week...to go shopping or go to lunch...And it really became all about our little house, nuclear family...I think you lose a big piece of your identity...After he was gone is when I realized everything revolved around what I was gonna do [for him]...You know I visited him [at the long-term care facility] every day. I fed him lunch every day...You've given up and lost friends, in part because I didn't call them, I didn't do things. It just all narrowed down just to our little house. (Emily)

You know, so, you've lost everything, and you have to reinvent who you are. You have to figure out what to do with your time that you spent with this person...All you feel is the loss... the loss of someone to care about and the loss of your job, of being a caregiver. So, it's, I mean, it's basically like retirement...What do I do now?...I had to figure out a new pattern for my life...But, it's just hard to find a new pattern, especially when you were happy with the old one. The old one a long time ago. (Nancy)

The grief process. “The grieving process sure is hell” (Marie). Multiple feelings of loss were a significant challenge to resilience after the death of their spouse. While SDCs were grieving the loss of their spouse, they were also grieving the loss of the plans they had made for their future that included the hopes and dreams for their spousal relationship. For many SDCs, feelings of sadness and loss took time to process and were often complicated by feelings of guilt in how they performed their caregiver role and the guilt of surviving their spouse. These feelings of loss for SDCs were pervasive throughout bereavement.

Well, it takes a while. Especially, I'll call it the first year. And I think, it's just a personal internal feeling...when you should stop grieving. People are like "get over it," you know. People are looking at me "like are you ok? You need to get over that." (Dawn)

Discussion of the grief process often focused on milestones and special occasions related to the anniversary of their spouse's death and familial relationships.

Our anniversary is coming up this month, so that will be a little pesky...I am moving on...[My friends] contacted me and made sure I was okay...And that's huge because they don't understand the dementia journey, most people don't...and the special occasions that come and go. (Susan)

Caregivers spoke of internal and external expectations surrounding the grief process adding another layer to the challenges of bereavement. These challenges often manifested in the caregiver's grief process being questioned in some way.

But there's also family expectations, and... his siblings, different expectations on their part...his sister felt almost like her loss was greater than mine...I was frustrated by that...if you really loved him you'd be falling apart right now...and you were not sad enough, or you were not feeling the loss...and that was hard...But it still was an emotional thing. (Emily)

All the SDCs reflected on grief being a non-linear and ongoing process. They all acknowledged that some days were better than others and that they felt it would just take time to process and deal with their grief.

And the grieving process sure is hell...you grieve the rest of your life, I guess, for that...Now you're here and it's a different place than you were before...it's almost an exciting time in some ways, but it's also terrifying...you don't really know how things are affecting you, or how things will shake down...It takes a long time, to kind of come to the realization that yeah, it's just me now. Not everything is in relationship to Dennis, caring for him...In some ways it's freeing. I can go out now. I can do these things. Then you feel guilty because you can do those things and - because they're gone. (Marie)

Supports to resilience.

Connections. Connections for SDCs were essential to supporting resilience during the bereavement phase of the caregiver journey. Connections to self, others, and community stood out during discussions of life after caregiving as important elements in supporting caregivers in their everyday lives. When asked what was helpful during bereavement, SDCs identified connections as essential to their ability to cope following the loss of their spouse and as a continued support of resilience throughout the bereavement phase.

Connections to self. Connections to self are represented in caregiver reflections around “finding yourself,” (Emily) acknowledging that “you are not the same person,” (Marie) and finding ways to merge one’s former selves before and during caregiving with their current self

after caregiving. SDCs connected to self through reflections on who they are as a person and how they wanted to spend their time.

I think what it was is going back down to say I am a good person. I'm a good person by myself. I just have to drag that piece back up again and find it. And remember what I am by myself as opposed to what I am as a couple...I am redefining myself and doing things for me...I think all of that is finding yourself and finding your path. (Emily)

So, I returned to some things and I kept on doing some things - the exercise, the crocheting, the writing, and then I also did end up going back to work on a real part time basis and did some volunteering. And so those were things that led me in different directions...I don't know how - it's hard to describe. It's like, you've been there all along...It's a life changing experience. I am not the same person I was before I went through this. (Marie)

Connections to others. SDC stories of life after caregiving highlighted the importance caregivers placed on being connected to family and friends in supporting their everyday lives. SDCs found value in these relationships and the life roles that came out of these relationships.

It helped me to have my children around. And friends in the community...there were many, many expressions of support towards me that helped me cope...and the company of my [daughter and grandson] have helped tremendously...our children always give us some purpose. (Anna)

I find great joy in being with people, different people...these different circles of friends. And some intersect with each other and some don't know each other at all. But I'm thankful that I have those different groups because they all have different dynamics...I'm finding great joy, absolutely enjoying being with people. (Dawn)

Connections to community. Caregivers also stressed how connection to communities crafted around home, faith, and caregiving provided opportunities for belonging. Neighborhood and faith communities provided day-to-day support for many of the SDCs immediately following the death of their spouse. SDCs also expressed how they valued being a member of these communities and knowing that they had extra support if they needed it. Most of the SDCs also remained connected to their caregiving community following the death of their spouse. This connection also allowed SDCs an opportunity to give back by sharing their knowledge and experience with other caregivers.

I could not believe the support I got when Tom passed. There were people out of the woodworks coming and helping us. I don't think we cooked for a month. The guy across the street mowed the grass for the rest of the summer. I didn't know how blessed we were with all our community...it was our thousand points of light. (Betty)

I feel also blessed to belong to a church that I really belong to...Loving each other, taking care of each other. And, for me, that's a practice. It's being able to go to this church, be a part of this congregation. It's just kind of a reminder. There are a bunch of good people

out there and if we get together and practice together, we'll be a mighty force of lovers and out there giving that love, spreading that joy. (Dawn)

I just have a strong understanding now of how many people are out there as caregivers...If there's any way that I can help...I think that's why the members that have lost people quite a ways back, why they're still coming too...I think it's just the community feeling and being able to talk to somebody about how things really are. (Brenda)

Engagement in activities. When asked what has been helpful for Anna during bereavement, she was quick to say “SEWING! That’s been my passion for 100 years. I love it! It is kind of a therapy for me. I forget about everything” (Anna). Engagement in activities played an essential role in supporting resilience during the bereavement phase of the caregiver journey. In every interview, activities were indicated as a key factor in providing structure, satisfaction, and meaning to the lives of SDCs. The key elements of SDC engagement highlighted throughout the interviews were meaningful activities, learning and growing, and having purpose represented in your day.

Meaningful activities. Many SDCs acknowledged that having something to do to just to keep “busy” (Dawn), during bereavement served an important function in just getting them through the day, especially immediately following the death of their spouse. Engagement in meaningful activities, however, provided an enduring support to their resilience and was represented throughout all the interviews as extremely important to SDCs. Engagement in meaningful activities contributed to resilience by providing structure to their days and serving as

an avenue to accomplish what they needed and wanted to do in their lives as well as supporting who they wanted to be.

You've lost everything and you have to reinvent who you are. You have to figure out what to do with your time...It gives me a framework for my day. Get up and go for a walk, then do the Zoom, which is fun to see the people...And, also, intellectually stimulating...Then gardening...It helps you to have a picture of yourself. Who you are and who you want to be and what you want to do with your life? (Nancy)

I had a paddleboard. So, I can go out there for maybe a half hour or hour and that really [eases] the tension...I do that to this day. It makes me happy. You know, that's my safe zone and my happy place. So, that helped with the transition...I try and stay busy because time makes you reflect on a lot of times, the past. (Susan)

I have a mindset of not to stay in the house all day. Don't hide away in the house. Get out and do something. I have to admit, I use a lot of retail therapy...I just fill my time with trying to do something out of the house every day. I'll go have lunch by myself with a book or go have lunch with somebody else or go shop for clothes or go to the library. (Sherry)

Learning and growing. Another key element of engaging in activities to support the resilience of these SDCs was the process of learning and growing. They were interested in

learning new things, challenging themselves, and doing things that allowed them to grow as a person.

I'm a learner and I'm growing...I think part of the process, or part of the basis for some of these things, is also aging...It's like, I need to save my sanity here...I still crochet, I still write...I still play banjo and I'm learning to play guitar now!...There's no end of things I think about that I might want to try...It is exciting. (Marie)

Then I went, for the first time in, oh, 20, 30 years, I flew to Maine and stayed a week with my friend...That was huge for me because I was petrified, because TSA from 9/11...But now this was by myself, carrying my own luggage, checking my own self in, it was all - I was petrified. But I made it. (Susan)

Having purpose and meaning. Another factor related to activities that support resilience for these SDCs was the importance of having purpose and meaning in their everyday lives. Furthermore, it was important that the things they were doing in their lives contributed to that need of feeling like their lives had purpose and meaning. Engagement in activities, especially meaningful activities, supported their resilience by providing opportunities to feel that their lives had “purpose” (Betty) as well as to “feel needed” (Nancy).

I think our children always give us some purpose. Even when they're old...you never end being a parent... and everything that surrounds me seems to be a positive force for me. I

couldn't just pick one thing that is around me that is meaningful. I think everything that is around me gives me purpose. (Anna)

What is my frame of reference? How do I program my days so that they are meaningful?

OK, I guess, with like gardening, it's like pulling weeds, you can't stop. I mean, you always see another one. So, it makes you feel like you're needed, basically, I guess that's basically it, feeling needed and that gives me meaning. So, you know, if I can help someone else, then that makes me feel good. (Nancy)

Meaning-making. Our final sub-theme demonstrating supports to resilience is the process of meaning-making. This concept represents the stories of how SDCs made sense of their caregiving experience and how they strived to find meaning in this experience during the bereavement phase of the caregiver journey. Meaning-making took on multiple forms. SDCs worked to make sense of bereavement in a way that facilitated positive coping and supported resilience through personal perspectives and attitudes, honoring the memory of their spouse, and expressing gratitude.

Personal perspectives and attitudes. A key element of meaning-making that supported resilience for SDCs was having a “mindset” (Marie) that you are going to be able to “manage” (Susan) the bereavement phase of the caregiver journey. Some caregivers also stressed the importance of having a “positive attitude” (Dawn). These perspectives allowed SDCs to reflect back on their caregiver journey and prescribe meaning in the context of growth and resilience.

It definitely is a mindset...It's still that sense of, jeez, I made it through that. I'm still here. I must still be here for a reason. I'm pretty strong. I didn't fall apart...I know what's important and what's not important, and so I'm not messing around with all the things that are really not that important at all. (Marie)

Trying to have a different perspective and a different outlook...working through it, if you want to call it that...I think some of it is an internal thing. I think some of it is, again-- it's not spiritual, but it is that inner feeling, or whatever...sort of that "you've got this" or "you've always managed things and you're gonna manage this now." (Emily)

Honoring the memory of their spouse. The efforts of SDCs to honor the memory of their spouse played an important role in meaning-making by framing the bereavement experience as an opportunity to process grief and positively reflect on their caregiving experience. This supported resilience by connecting SDCs to their previous selves and remembering their spousal relationship before and during caregiving in a positive light. SDCs often reflected on the time around their spouse's death. They also shared stories, acts, and rituals that honored the life and memory of their spouse.

It's a process too of, I mean...it was an element of a good death. That's what hospice talked about - good death. And now I always use that term because I think that's so appropriate. That there's such a thing as a good death in this process that we go through...And, you're preparing for it, and in some ways you're ready, although you're never really ready...It's a life changing experience. (Marie)

You sort of relive it and think about it. I feel like his was a good death...I feel good about that. About having been there, and the music we played, and the things [we did], and talking to him during that...A lot of time and a lot of reflection and doing little things and day-to-day, and then at a year, reflecting back on what was going on for that week and everything that happened. I do feel like that time...helped me work through it. It just sounds silly, passing of birthdays and holidays and all those milestones that you get past a year and- it doesn't mean you don't miss them, but somehow you've dealt with most of the big things. (Emily)

I have a DVD that we made for Al's celebration of life and, at first, I would watch it at least once a week. At least once a week. And now I'm down to maybe once a month. I love to see that because it shows him as he truly was, how I want to remember him, as his happy go-lucky-self, you know. And, the guy that I fell in love with. So, that brings me joy. I had some memorabilia made from some of his things. Like, I made a pillow from his flannel shirts. I had quilts made for the girls out of his flannel shirts...and I had teddy bears made for my grandsons. (Susan)

Expressions of gratitude. Another finding related to meaning-making that supported resilience during bereavement was the amount of gratitude expressed throughout every interview. Gratitude served an important function in meaning-making by providing a way to appreciate their experience and positively frame it in a way that facilitated positive reflection and coping. SDCs spoke of gratitude in relation to both the larger experience of their caregiver

journey, including the bereavement phase, and the specific elements of that experience that made them feel “lucky” (Sherry), “fortunate” (Dawn), “blessed” (Betty), and “thankful” (Jill).

Caregiving makes you appreciate what you have...I tend to think of what I *do* have...I'm able to be thankful that I'm strong and I can [give back through volunteering] even though I'm 78...I can do it and I'm thankful. And I like to do it because it helps me to be thankful instead of saying "Ow, my big toe hurts." (Nancy)

I just feel blessed that I have the knowledge that I attained on the journey and the comfort of family, friends, God. I would not change the path that we took and how we did it...I feel so blessed. And I feel blessed with the people I met along the journey and the things that I was able to do, even on the journey...there's just so many things to be happy and thankful for that happened with him, and without him...I'm not going to dwell in the past. I'm moving forward, and that's what he would want. (Susan)

Discussion

This account demonstrates resilience as the dynamic process of SDCs' ability to navigate and overcome life challenges. The spousal dementia caregivers (SDCs) in this study experienced resilience within the context of their everyday lives. Their stories related to resilience were largely connected to their everyday activities, roles, routines, and relationships. This is of particular importance since these areas of everyday life have a bidirectional relationship with resilience, in such a way that higher positive levels of performance and participation in these areas not only support resilience but also become the outcomes of resilience (MacLeod et al.,

2016). For SDCs in this study, external connections, meaningfulness, self-care, self-acceptance, positive perspectives, independence, and altruism (Bolton et al., 2016) both supported their resilience during bereavement and became the product of that resilience in the form of engagement in meaningful activities, satisfaction in life roles, structured daily routines, and meaningful relationships. This bidirectional relationship is also observed in the ways adaptive coping styles, optimism and hopefulness, and positive emotions (Martin et al., 2015) supported SDC resilience while also being further enhanced throughout the bereavement process. This interdependent relationship between resilience and everyday life is important to keep in mind as we examine the ways in which SDCs experienced resilience in their everyday lives.

SDCs' understandings of resilience and the challenges to resilience faced during the bereavement phase of the caregiver journey align with current literature addressing resilience, caregiving, and bereavement (Gibson et al., 2019; Peacock et al., 2016). These caregivers conceptualized resilience in terms of personal attributes and experiences as well as the ability to cope with their grief and loss through acceptance, flexibility, and willingness to learn and grow from the experience. They also expressed how one of the biggest challenges to resilience was being alone. Considering the importance social relationships have in supporting resilience, and how these caregivers identified connections to others as a significant support to their resilience, social isolation and loneliness pose significant risks to resilience during bereavement (Donnellan et al., 2015). Being alone and feelings of loneliness are intrinsically linked to the challenges these SDCs faced related to the grief process. Grief and coping play a prominent role in the experience of resilience in the context of the caregiver journey and were expressed throughout caregivers' stories of understandings, challenges, and supports to resilience. Changes in everyday activities also pose significant challenges to resilience during the caregiver journey and played a

significant role in the everyday lives of SDCs (Mattock & McIntyre, 2016). The structure and purpose of their daily life had been disrupted with the loss of their spouse and their role as an active caregiver. These caregivers discussed challenges related to not only *what* they did (activities) but also *how* they did it (routines) and *who* they did it with (roles and relationships). These discussions highlight the multi-dimensional nature of the challenges to resilience these SDCs faced. It is important to consider these challenges of being alone, changes in everyday activities, and the grief process as we move into discussions around what SDCs found helpful and supportive to resilience during the bereavement phase of the caregiver journey.

One of our most prevalent findings centered on relationships and connections. SDCs identified being alone and the loss of relationships as some of the biggest challenges to resilience. In turn, they also identified connections, especially with others, as one of the biggest supports to resilience throughout the bereavement phase of the caregiver journey. They consistently and directly credited connections with others and their communities as supporting their ongoing resilience during bereavement. The value SDCs found in these connections aligns with current understandings of resilience that highlight the social factors that support resilience, such as strong, positive relationships, supportive emotional and social networks, social connectedness, positive contact with family and friends, greater participation in social activities, community involvement, and altruism (Bolton et al., 2016; Fullen & Gorby, 2016; Hildon et al., 2010; Hildon et al., 2008; MacLeod et al., 2016). What our findings add to this conversation is that these connections and relationships were often discussed within the framework of everyday experience and the context of engagement in everyday activities.

Engagement in activities, particularly meaningful activities, held the utmost importance in supporting resilience for these SDCs. This was expressed through their countless accounts of

how everyday activities, roles, and routines were instrumental in supporting their resilience. From an occupational lens, most of these supports fall under the category of occupation in that they represented what these caregivers needed and wanted to do that gave meaning and purpose to their everyday lives. This is of particular interest to occupational therapy since occupation serves as the vehicle for meaningful engagement in everyday life. Viewing life experiences from an occupational lens centralizes the role of occupation, or how we occupy our time, as an influencing factor in these experiences. Engaging in meaningful occupations is particularly beneficial, since it contributes to an individual's sense of self and purpose in life (Law et al., 2002). In terms of resilience, occupation can be conceptualized as the means by which individuals adapt to changing conditions and challenges (Schultz & Schkade, 1992). SDCs were able to articulate the benefits occupation had in supporting their resilience and how these occupations provided a connection to self and purpose in their everyday lives. SDCs identified occupations such as volunteering, taking care of pets, and spending time with friends as expressions of their identity and a way to add purpose and meaning to their daily life.

Engagement in meaningful occupations also is associated with positive physical and mental health, subjective well-being (Everard et al., 2000; Stadnyk et al., 2010; Wilcock, 2005), and a good quality of life (Molineux, 2009). SDCs directly connected occupational engagement to their health and well-being and identified everyday occupations such as exercising or gardening as instrumental in coping with challenges and supporting their overall resilience. Molineux (2009) has emphasized the need for understanding the context in which an occupation occurs to truly understand occupation and occupational engagement. For these SDCs, the context of the bereavement phase of the caregiver journey adds an additional level of using occupation and their occupational engagement as a vehicle for resilience in addressing the everyday

challenges related to bereavement. This point further supports our case for the need to enhance our understanding of the bereavement phase of the caregiver journey in order to better understand the everyday experiences of SDCs. This is especially true considering the essential role occupation and engagement in meaningful activities played in the everyday resilience of these SDCs.

During their discussions of the bereavement phase of the caregiver journey, all the caregivers expressed concepts related to resilience in ways that linked those concepts closely to ordinary aspects of their everyday lives. SDCs identified that engagement in everyday activities such as pet care, connecting with friends, gardening, and house maintenance contributed to a daily routine that provided structure and purpose to their everyday lives and supported their overall resilience. They also discussed how everyday relationships with others and the roles that comprised those relationships, such as mother, friend, neighbor, or support group member, supported their ongoing resilience through connection and engagement in shared activities. Resilience being rooted in everyday experience for SDCs during the bereavement phase of the caregiver journey draws attention to the “everydayness” of resilience and moves our current understandings of resilience forward. These findings expand on the idea of conceptualizing resilience as “a social process arising from mundane practices of everyday life and situated in person-environment interactions” (Lenette et al., 2012, p. 637). Masten (2001) refers to this everydayness as “ordinary magic” where adaptation is a natural human process that should not be considered the exception but, rather, the normal response to challenges.

Much of the research on resilience has traditionally focused on extraordinary circumstances resulting in extreme challenges or trauma but researchers are beginning to highlight the common nature and daily process of positively adapting to everyday challenges

(Bonanno, 2004; Lenette et al., 2012; O'Dwyer et al., 2017; Ong et al., 2009). While SDCs do experience the emotional and challenging circumstances of active caregiving followed by the tragic and life changing death of their spouse, these caregivers still embedded these experiences within the context of their everyday lives. Although they acknowledged that “you’re never ready” (Betty) for the death of a spouse, they viewed the passing of their spouse as an expected part of the caregiver journey. These caregivers also storied resilience during this bereavement transition in ways that reflect the everyday, such as the disruption in the daily routine of visiting their spouse or sharing a meal with them. The things caregivers found helpful following this transition were also often expressed as everyday “little things” (Nancy), such as getting dressed, meeting a friend for coffee, or walking the dog.

The everydayness of resilience also functions within a dynamic process that allows for varying levels of resilience in response to challenges over time and within everyday contexts (Lenette et al., 2012). The dynamic nature of resilience also allows for multiple and possibly unexpected resilience trajectories, or pathways to resilience (Bonanno, 2004). The SDCs in this study shared many stories that represented the inconsistencies in their feelings related to resilience and their ability to “get through” (Marie) the bereavement process. Although these caregivers reflected on their experience and reported generally feeling resilient, they explained that “somedays are better than others” (Anna). The everydayness of resilience permeated all aspects of SDCs’ understandings of resilience as well as what they found challenging or supportive during the bereavement phase of the caregiver journey.

Meaning-making emerged as a crucial support to resilience for SDCs and advances our understanding of resilience in the context of the bereavement phase of the caregiver journey. Kessler (2019) asserts that finding meaning, or finding a way to make sense of events in a

manner that is meaningful to an individual, during the grief process can contribute to healing and resilience. Meaning-making has strong ties to resilience and can be viewed as a way of coping with life challenges (Eakman, 2015; Park, 2010). Ways in which SDCs attributed meaning to their caregiver journey, including bereavement, such as finding ways to positively frame their experience and find gratitude in their experiences represent benefit-finding and serve to support resilience by providing an avenue for positive coping (Tennen and Affleck, 2002).

A salient feature of meaning-making for these SDCs included expressions of gratitude. Gratitude was conveyed in every interview in a variety of ways that often acknowledged its role in supporting resilience, and drew attention to the interconnectedness of resilience, relationships, and engagement in meaningful activities. SDCs often expressed gratitude as they reflected on the passing of their spouse as being a “good death” (Marie). They also expressed feelings of gratitude to connections with others and their ability to engage in occupations that provided purpose and meaning in their lives. Perceiving a spouse’s death as “a good death,” strong support systems, and gratitude have been found to be instrumental in resilience during bereavement for SDCs by providing a way to process grief and appreciate their experiences (Gibson et al., 2019). Many SDCs also provided expressions of meaning in their stories that honored the memory of their spouse such as feeling their spouse was with them if they saw a hummingbird or making mementos out of their spouse’s favorite shirts. They expressed how these acts provided comfort and continued to connect them to their spouse.

Together the findings from this study provide an enhanced understanding of resilience from the perspectives of SDCs during the bereavement phase of the caregiver journey. This study adds to current knowledge regarding resilience and dementia caregiving by situating our examination of resilience within the context of the bereavement phase of the caregiver

experience. Our findings also deepen our understanding of the role of everyday experience and occupation in influencing resilience for SDCs during the bereavement phase. The findings draw attention to the personal, contextual, and complex nature of resilience in everyday life for these SDCs. These findings also remind us of how interconnected the elements of resilience are within the context of our everyday lives.

Implications for occupational therapy practice. The findings in this study illuminate the role everyday experiences play in supporting resilience for SDCs during the bereavement phase of the caregiver journey. Since resilience shares a strong relationship with health and well-being (Manning et al., 2016; Reich et al., 2010), it is beneficial for occupational therapists to understand the reciprocal relationship between resilience and everyday experience. Resilience was extensively woven into daily routines that framed the activities involved in meaningful engagement in occupations such as gardening, exercising, and playing an instrument. Relationships and connections with others supported resilience and produced valued roles for SDCs including mother, neighbor, friend, and community member. Given occupational therapy's focus on these areas of everyday life, this provides a distinctive opportunity for occupational therapists to address resilience in everyday practice. It is important for occupational therapy to focus on how everyday supports to resilience such as connections, relationships, meaningful engagement, occupations, and opportunities for meaning-making can be integrated into practice. Practitioners should work towards identifying and addressing the needs of SDCs both dyadically and independent of their caregiver role during the entirety of active caregiving and leverage the strengths of everyday experience and occupation to support resilience throughout the caregiver journey, including bereavement, to provide continuity of care for the caregiver. Occupational

therapists should also work towards deliberately embedding strategies into practice that support caregiver resilience from the beginning of the caregiver journey into bereavement.

Limitations and future research. There are several limitations in this study. The majority of the SDCs in this study reside in the same geographical location and are active in their local caregiving community. SDC involvement in similar local supports and services may reinforce the homogeneity of this study population. These commonalities may decrease the range of variation achieved such as the experiences of more socially isolated SDCs or caregivers that are experiencing more complicated grief over the death of their spouse (Bonanno, 2004). Furthermore, all the caregivers that chose to participate in this study were women. While we recruited for both men and women, no men agreed to participate in this research, possibly further limiting the amount of variation in our findings. The lack of male participation in this study is consistent with current literature across health disciplines that report a decreased amount of participation and representation of men in caregiver research (Houde, 2002). Data collection was interrupted by the COVID-19 pandemic, which resulted in the majority of interviews being performed remotely, during the pandemic. We have no clear indication of how the situation surrounding the pandemic may have impacted our findings.

Additional research is warranted to explore the experience of the bereavement phase of the caregiver journey for a larger and more inclusive sample of SDCs, including male caregivers. Current research addressing the male dementia caregiving experience is limited and has yet to explore the relationship between the male caregiving experience and the health and well-being of men throughout their caregiver journey (Robinson et al., 2014). Additional research is needed to increase our understanding of the distinct ways everyday experience and occupation interact with resilience in the context of the caregiver journey, including bereavement for SDCs. Research is

also needed to determine the most effective ways to incorporate the use of occupation into everyday practice as an intervention tool to address the needs of SDCs throughout the entire caregiver journey and support their ongoing resilience.

Conclusions

In this study, we highlighted the voices of SDCs to craft a larger view of the caregiver journey to include bereavement and deepen our understanding of the nature of resilience for SDCs by exploring their lived experience following the death of their spouse. For these SDCs, the caregiver journey did not end with the death of their spouse. Their resilience during this bereavement phase of the caregiver journey was rooted in their everyday experiences. The essential supports to resilience for SDCs during bereavement were connections, relationships, engagement in activities, occupations, and meaning-making. Enhanced understanding of resilience in the context of the bereavement phase of the caregiver journey is essential for occupational therapists in providing meaningful supports and services to caregivers throughout the entirety of the caregiver experience.

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CHAPTER 3: STUDY 2

Spousal Dementia Caregivers' Conceptualizations of Life During the Bereavement Phase of the Caregiver Journey: A Phenomenography

Every caregiver experience is distinctive in nature and can be viewed as a series of elements and events that create a caregiver journey (Peacock et al., 2014). Becoming a caregiver to your spouse with dementia involves an unexpected life transition (Hooper & Collins, 2016). This life transition requires persistent adjustment and adaptation to meet the daily challenges of caregiving, requiring caregivers constantly to reframe life plans to meet the care needs of the individual with dementia (Blair, 2000). For many caregivers, the caregiving journey is marked by a series of key transitions that include: obtaining a diagnosis, adapting to frequent changes, managing care at home, losing ability to manage care at home, transitioning the loved one to long-term care facility, experiencing the loved one's end of life, and grieving the loss of the loved one (Peacock et al., 2014). Each transition brings with it new and different care responsibilities to meet the needs of the individual with dementia, as well as changes in caregiving demands for the caregiver. The increasing demands of caregiving often results in stress, depression, and self-reported decreases in physical health for the caregiver (Connell, et al., 2001). As caregivers approach end-of-life care, focus begins to shift towards preparing for the death of the care recipient and the end of the caregiving experience. However, Peacock et al. (2014) argues that the caregiving journey does not end when the individual with dementia dies but, rather, ushers in the final stage of the process of caregiving.

This final stage of the caregiver journey can be conceptualized as the "bereavement phase." Bereavement is the "condition of having experienced a loss" (Hoppes & Segal, 2010, p.

134). Loss from the death of a spouse is considered one of the most stressful life transitions one may encounter during their life course (Field et al., 1999). Field et al. explains that the death of a spouse requires a person to not only reimagine their life in relation to their hopes and plans for their future, but it also initiates the construction of a new identity independent of their spouse. The death of a spouse also creates a disruptive and difficult role transition requiring a period of time to readjust to everyday life (Feldman, 1999). Given its significance in the lives of spousal dementia caregivers (SDCs), bereavement also serves as a “turning point” in the caregiver journey. Turning points are “significant life events, experiences, and realizations,” and “constitute a fundamental shift in meaning, purpose, or direction of a person’s life” (King et al., 2003, p. 186). Turning points can be positive or negative (Turner & Avison, 1992); cumulative episodes or sudden, single events (King et al., 2003); gradual understandings or sudden illuminations; and personal, subjective experiences or situational occasions (Denzin, 1989). Reflecting on turning points in the context of one’s life story allows individuals a chance to construct and interpret past events, in order to clarify the meaning of these experiences, preserve their sense of identity, and increase awareness of personal growth in light of these experiences (Hildon et al., 2008; Leonard & Burns, 2006). Creating narratives, including reflecting on the turning point of losing a spouse, provides individuals with a valuable method to understand, or “story,” the experiences of SDCs in the context of the bereavement phase of the caregiver journey (Gibson et al., 2019).

A narrative is a spoken or written account, or story, pertaining to a series of connected events. Narrative is viewed as a way by which individuals can make sense and construct meaning around life experiences (Hasselkus & Murray, 2007). Older adults “story” their lives around significant events throughout their lifetimes and participate in an active, reflexive process that

enables opportunities for resilience through learning, growth, and wisdom (Gattuso, 2003; Nelson-Becker, 2013). This process has proved beneficial for the therapeutic reflection of SDCs during both the active and the bereavement phases of the caregiver journey (Danforth & Glass, 2001; Holtslander et al., 2017). The caregiving journey is personal, contextual, dynamic, multi-dimensional, and immensely complex. It tells a unique story of a caregiver's experience. Exploring the story of the bereavement experience can provide a deeper understanding of the caregiver journey and the ways in which caregivers experience life after caregiving.

Stories that represent the dementia caregiver journey or examine the shared experiences of dementia caregivers are growing in the literature, especially during active caregiving. Quinn et al. (2008) examined the subjective experience of spousal caregivers during the early stages of dementia caregiving and their ability to navigate the transition into the caregiver role. Shim et al. (2012) conducted a comparative qualitative analysis to explore how the experiences of SDCs differ. Stories of active caregiving help to frame how SDCs think, feel, and function in their everyday lives during their caregiver experience. While studies examining the qualitative nature of active caregiving for SDCs provide valuable insights into the caregiver journey, much less is known about the subjective experience of SDCs during the bereavement phase.

Due to the high level of risk for negative health and well-being impacts caregivers experience during the active phase of the caregiver journey, it is important for health professionals to be mindful of how the active caregiving experience may influence and shape the caregivers' everyday lives during bereavement (Schulz et al., 2008). In addition, caregivers will be experiencing grief and mourning related to the death of their spouse requiring adaptation and "reorganization of the survivor's sense of self" (Hagman, 2001, p. 19). This bereavement process also includes adjustment to new roles and routines that directly impact engagement in everyday

life (McIntyre & Howie, 2002). For SDCs, adjustment to the loss of their spousal role is coupled with the loss of their role as an active caregiver (Hoppes & Segal, 2010). For many SDCs, the role of caregiver provided great purpose and meaning in their lives (Lloyd et al., 2016).

The caregiver journey, including bereavement, constitutes a complex, lengthy and significant life experience for SDCs that impacts many, if not all, facets of their lives. We are beginning to understand the factors that facilitate the bereavement process for SDCs such as social supports, formal support programs, and engagement in activity (Peacock et al., 2016). However, Gibson et al. (2019) indicates that much of the literature addressing the supports and services for SDCs remains situated within the context of active caregiving. This study provides a crucial step in building our knowledge of how to best address the supports and services for SDCs within the context of the bereavement phase of the caregiver journey. By examining how SDCs, themselves, understand or conceptualize their experience during the bereavement phase of the caregiver journey, we capture a clearer contextual understanding of their everyday life. With the number of caregivers rising to meet the growing needs of an aging population, it is essential for therapy-focused professionals to understand the caregiving experience in a more in-depth way. With this understanding, therapists are more prepared to provide informed and meaningful supports and services to SDCs during the bereavement phase of the caregiver journey.

The purpose of this study is to enhance our understanding of the different ways SDCs experience the bereavement phase of the caregiver journey. We will do this by examining not only what SDCs experienced during the bereavement phase but also how they conceptualized their experiences. These conceptualizations illuminate key features of the bereavement experience and provide contextual understanding of the everyday lives of SDCs. The following questions guided this study: How do SDCs conceptualize their experience during the

bereavement phase of the caregiver journey? How do these understandings of the bereavement phase impact the everyday lives of SDCs?

Methods

Research design. This study used a qualitative design with a phenomenographic approach (Marton & Booth, 1997) to highlight the voices of SDCs in examining the varied ways they conceptualize their experience during the bereavement phase of the caregiver journey. This approach allows us to go beyond the examination of everyday experience by also exploring how SDCs understand this experience. It also provides an opportunity to address the ways in which different understandings of the bereavement phase relate to one another and interact with the everyday lives of SDCs. Our aim in using a phenomenographic approach is to provide a collective analysis of the different ways SDCs in this study conceptualized their experience during the bereavement phase of the caregiver journey (Akerlind, 2012). This approach allows us to shift our focus from examining the bereavement phase, itself, to exploring how SDCs experience this bereavement phase. This shift provides a conceptual framework for our understanding of the experience of SDCs during the bereavement phase of the caregiver journey.

Participants. The participants in this study included ten women, ages 62-85 years. (See Table 3.1 for participant characteristics.) Eight of these women lived in Northern Colorado while one lived in central Colorado and one lived in New Jersey. To be included in this study, each participant needed to have been a spousal caregiver to someone with dementia who had passed away at least six months prior to participation in the study. By recruiting caregivers whose spouse with dementia had died at least six months prior to this study, the researcher helped ensure that those caregivers had had time to process and reflect on the loss of their loved ones (Bentley and O’Conner, 2015; Hovland-Scafe & Kramer, 2017). The first author used purposive

criterion sampling techniques (Patton, 1990), to recruit participants who fit our study criteria and supported the objectives of the study. Women and men across the country were recruited to take part in the study. She emailed representatives from local, state, and national organizations specializing in dementia services and provided a short summary of the study for them to post online and send electronically to potential participants. Additional participants were recruited through snowball sampling (Patton, 1990), in which SDCs already familiar with the study reached out to other SDCs they thought might be interested in participating in this study.

This study was interrupted by the COVID-19 pandemic. COVID-19 is a highly contagious and potentially life-threatening disease discovered in 2019 that caused a world-wide pandemic resulting in recommendations to physically isolate from others (WHO, 2020). The pandemic slowed recruitment efforts by temporarily halting this research project and restarting the project among uncertainties related to guidelines around safe return to research activities. We adjusted to social distancing guidelines by moving all interviews to a phone or virtual platform. Recruitment efforts continued to be impacted by the psychosocial impacts of the pandemic coupled with the nature of the topic of bereavement. Some potential participants ultimately decided that they just didn't have the emotional capacity to participate in the study.

Ethical considerations. Ethical approval was granted through the Colorado State University IRB process, #19-9322H. The consent form was approved by the Human Research Committee at Colorado State University. Participants read and signed the consent form before being included in this study. The consent form included a brief background to the study, an overview of the interview process, the overall objectives of the study, as well as the general expectations for participation, as well as the potential risks involved for those interested in

Table 3.1

Participant Characteristics

Participant	Spouse Diagnosis	Age	Years Married	Caregiver Age at Diagnosis	Spouse Age at Diagnosis	Spouse Age at Death	Years Spouse was Diagnosed	Years of Active Caregiving	Years Since Death of Spouse
Emily	Dementia	62	26	45	53	66	13	13	4
Marie	Lewy Body Dementia	67	20	60	60	64	4	5	3
Sherry	Progressive Supranuclear Palsy	81	53	74	74	80	6	6	1
Nancy	Vascular Dementia	78	39	66	77	83	6	4	6
Susan	Alzheimer's	67	48	62	67	71	4	4	1
Brenda	Parkinson's with Dementia	83	58	63	62	79	17	5	3
Anna	Alzheimer's	85	58	79	79	85	6	5	1
Jill	Frontotemporal Dementia	72	8	62	62	69	7	5	3
Dawn	Mild Cognitive Impairment	62	31	52	60	66	6	6	4
Betty	Lewy Body Dementia	65	Separated	61	58	61	3	5	1

participating in the study. All participants were verbally reminded before each interview of confidentiality and their right to discontinue participation in the study at any time during the research process.

Data collection. The first author conducted semi-structured interviews with open-ended questions to capture the caregiver experience. The interview questions allowed participants to share their stories in a way that featured their unique perspectives and insights into their own experiences. (Please see Table 3.2 for examples of the interview questions.) Each participant completed two in-depth interviews, which lasted, on average, 45-75 minutes. The first interview focused questions within the context of the participant's active caregiving through the end of life experience and provided an opportunity to build rapport. The second interview framed questions within the context of the bereavement phase of the caregiver journey. Demographic data were collected using a caregiver questionnaire, which contained items that addressed current caregiver age and age at time of the loved one's diagnosis, actual diagnosis of spouse, spouse's age at time of diagnosis and at death, length of time caregiver was married to spouse, and length of time participants identified as a caregiver (See Table 3.1 for participant characteristics).

Table 3.2

Examples of Interview Questions

<p>Tell me about your caregiver experience. What was helpful to you during caregiving? What did you find challenging during caregiving?</p> <p>Tell me about your life after your spouse passed away. What was helpful to you during this time? What did you find challenging during this time?</p> <p>Do you still consider yourself a caregiver? - Why or why not?</p> <p>Do you think that the time after your spouse passed away is still part of the caregiver journey? - Why or why not?</p>
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Data for this study was collected in two un-planned stages. The first three pairs of interviews were completed before the arrival of the 2020 COVID-19 pandemic. The first three participants were able to choose the location of their face-to-face interviews at a public meeting place or in their home. The additional seven participants were required to complete their interviews virtually due to in-person meeting restrictions during the COVID-19 pandemic. All virtual interviews were conducted using Zoom[®], an online video conferencing platform. Interviews from the first three participants were audio recorded using a portable digital voice recorder while interviews from the last seven participants were recorded through the virtual Zoom[®] platform. All interviews were transcribed verbatim.

Data analysis. The research team completing the data analysis consisted of the first author, another researcher, and a research assistant. Data analysis followed Dahlgren and Fallsberg's (1991) seven steps for phenomenographic analysis. The first step in our data analysis process was *familiarization* with the data. The first author/interviewer listened to the audio recording of each of the three participant's first interviews in order to gain a general sense of the interview and become familiar with the data (Braun & Clarke, 2006). The interviewer then listened to the interview for a second time while taking notes of content that stood out in her conversations with the participants. These interview notes from the first interviews were used by the first author to generate preliminary codes and propose thematic categories. Questions related to the initial proposed categories were used by the first author to conduct early member checks with the participants at the beginning of their second interview. The second step, *condensation*, began by including all three team members in the process of breaking the interviews into "meaning units." Each interview transcript was reviewed and conversations that were related only to the bereavement phase of the caregiver journey, not the active caregiver phase, were

identified and used to create the data pool for this study. Following the completion of both interviews for each participant, the researchers reread the collection of pooled bereavement data, as a whole, before moving on with coding. Members of the research team then independently performed manual open coding to capture initial conceptualizations of the data (Charmaz, 2014). Following the open coding process, each team member independently and manually conducted axial coding to begin making connections between the initial codes (Corbin & Strauss, 2015). The third step, *comparison*, involved the team members comparing the coded “units” to identify similarities and differences. The research team then completed the fourth step, *grouping*, by working independently to develop initial categories based on the patterns emerging from the coded data, and then together compared, refined, and consolidated the categories.

Up to this point, the research team manually worked with the data to allow independent coding, which decreased the potential influence of the researchers on each other during the coding process. At the conclusion of the team’s data analysis processes, the first author transferred all interview transcripts and categorized codes to a qualitative data management software, NVivo®. All subsequent steps in the data analysis for this study were conducted using the NVivo® software. The fifth step, *articulating*, involved identifying the essence of each category. In step six, *labelling*, the essence for each category is described and characterized. This final set of categories in a phenomenographic study is called the *outcome space* (Akerlind, 2012). It should be noted that steps 3-6 are repeated in an iterative process to further refine and focus the categories. The seventh and final step, *contrasting*, included discussion of the relationships between the four categories that make up the outcome space for this study.

Issues of trustworthiness. The research team addressed the trustworthiness of our study methods and proposed findings in several ways. We used bracketing to address credibility by

identifying and setting aside our assumptions and experiences with regards to the caregiver journey, including bereavement (Ashworth & Lucas, 2000). We used purposive criterion sampling (Patton, 1990), to identify and recruit participants who were able to express articulately the experience of SDCs during the bereavement phase of the caregiver journey. The first author performed a formal member check at the beginning of the second interview and informal reviews at the end of each interview. This allowed the interviewer an opportunity to review interview content with participants to get their feedback on our emerging findings and interpretations of the data throughout the interviews (Savin-Baden & Major, 2013). The use of annotations, memoing, and journaling provided an audit trail and chronicled decisions related to the research process to ensure continuity throughout the study (Birks et al., 2008). The research team performed all initial coding of each transcript as well as the preliminary categorization of these codes independently. We then collaborated to produce higher level codes, categorizations, and themes. The research team also included an outside coder (the research assistant), who was unfamiliar with the study throughout the data analysis process. One member of the research team served as a peer reviewer to provide an outside check of codes and categories. We believe that these activities increased the “quality” or rigor of our study’s findings, through the use of triangulating analysts (Savin-Baden & Major, 2013).

Findings

The structure of the outcome space. Four qualitatively different ways the SDCs conceptualized the experience of the bereavement phase of the caregiver journey were identified through the data analysis process: 1) the bereavement phase as an extension of caregiving, 2) the bereavement phase as moving on from caregiving, 3) the bereavement phase as an evolving process, and 4) the bereavement phase as a time for personal growth. These four conceptual

categories constitute the outcome space and serve to describe the SDCs' understandings of everyday life during the bereavement phase of the caregiver journey. Our outcome space is depicted in Figure 1. SDCs did not understand their experience during the bereavement phase from only one of these categories, or perspectives, at a time. Rather, due to the dynamic and reciprocal nature of our outcome space, SDCs often occupied more than one category at any given time during the bereavement phase. Furthermore, each category had the potential to influence other categories within the context of everyday life during the bereavement phase of the caregiver journey. We explore these relationships within the outcome space later in our findings. First, we will examine each individual category of the outcome space. Excerpts and stories from the interviews highlight the voices of the SDCs in depicting the varied conceptualizations of life after caregiving.

Bereavement phase of the caregiver journey as an extension of caregiving. All the SDCs in this study considered the bereavement phase a part of their overall caregiver journey. Some of the SDCs spoke of the details involved after their spouse had passed away that kept them connected to the caregiver role such as “paperwork” and “processing things that belonged to [their spouse]” (Anna). Other SDCs described needing a “month” (Susan) up to a “year” (Emily) to adjust to not planning their days around the care of their spouse. Most of the examples the SDCs shared were linked to their own identity and desire to give back to other caregivers.

For some of these SDCs, caregiving was a role they had identified with throughout their lives, while others found caregiving an acquired role they would now carry with them indefinitely. For the SDCs that felt caregiving had always been a part of their identity, they took pride in this role and derived great purpose, meaning, and joy from being a caregiver.

Caregiving is kind of like my life...I guess we were always taught to do things for other people. And that's how you feel good about yourself. So, that's basically what I try to do.

(Nancy)

I think [caregiving] is something that I've done most of my life....having a daughter in town and...now this grand-daughter...I said "Would you allow me to help you with caregiving?" (Dawn)

Many of the SDCs expressed a need to help others going through the dementia caregiving journey as a way of “giving back” (Brenda) to the caregiver community by sharing their hard-earned wisdom. For these SDCs, it was important for them to continue supporting other caregivers who were still going through the process. Many of these SDCs noted how much others had helped them along their journey, and they felt the need and desire to do the same for other caregivers.

And then, with my job, I also work with, I guess, share my time with other caregivers now in the support group that I facilitate and so it's like, that's another really important way that I carry on what I went through and use it for what I hope is to...make things better for other people...to give back in some way. (Marie)

My goal is to teach other caregivers, who go in unprepared. Like I was. So, that's my focus right now. Is to try to help other people...I'm still caregiving in a sense. But it's a

different way. I'm caring for the people in the support group. I still go...because I feel like I may have something to offer...and add some wisdom to your experience. (Sherry)

Bereavement phase of the caregiver journey as moving on from caregiving. Many of the SDCs viewed the bereavement phase of the caregiver journey as a period of moving on from the caregiver role. Susan described caregiving as being a “past tense of [her] life” explaining that she’s “happy to help anyone along their journey but not dwelling so much on the past. It’s good to move on.” Other SDCs shared this sentiment of moving forward and not wanting to “live in the past” (Brenda).

For some SDCs, moving on from caregiving was a series of feelings, thoughts, and actions that developed over time. As SDCs moved away from caregiving, they often changed elements of their everyday lives such as activities and relationships as well as taking on new life roles.

“I need to move on. I need to do something"...I took my wedding rings off and it was really like a symbolic thing of saying, "I'm not gonna dwell on this anymore. I really need to get out and get involved in things"...That's when I decided I really needed to leave my job at [Dementia Organization] and do some happy things. Do some things where what our topic of conversation wasn't about the sadness and the grief and the loss...I got involved in the theater in volunteering there...it was a positive thing...It's moving in a different direction. (Emily)

SDCs often would describe the bereavement phase as a “retirement” from their role as a caregiver (Jill). For these SDCs, caregiving had served as a full-time job that shaped the makeup of their everyday lives. Caregiver also served as an essential and defining life role for these SDCs.

What I said to people, besides losing your best friend and your husband, you lost your job...So, with him on your mind all the time, what are you going to do? How are you going to do it? How are you going to make him happy? Then, suddenly, that's not there. All you feel is the loss, the loss of someone to care about and the loss of your job, of being a caregiver. So, it's, I mean, it's basically like retirement. (Nancy)

Other SDCs stressed the importance of taking advantage of the “fresh start” that this phase of their life provided (Dawn). These SDCs shared stories about how life after caregiving provided opportunities to try new things like playing the banjo (Marie), joining groups to play pickleball (Susan), or meet new people (Betty). For a few of these SDCs, this was the first time in their lives that they had lived alone.

I moved to a townhome in May. And I absolutely love it...I had that alone time...to adjust to being alone, into a new neighborhood, a new routine...And [the neighbors] know me as me...They didn't know me before, or Al...It was a fresh start. (Susan)

Bereavement phase of the caregiver journey as an evolving process. The bereavement phase also was understood by many of the SDCs as an ever-changing and evolving process. They

spoke of the caregiver journey, including bereavement, as a “life changing process” (Marie). Some SDCs also described the bereavement phase as being a slow process with no clear beginning or end and progressing in a non-linear fashion. Emily reflected that “it wasn't like a light switch came on or off” but something that happened over a course of time. SDCs shared thoughts and stories that illustrated the disorganized nature of the bereavement phase and the sometimes-conflicting feelings experienced during life after caregiving.

And that the process itself- and caregiving itself is a living thing...It doesn't even have a beginning and an end necessarily...In some ways, it's an exciting time but it's also terrifying...you don't really know how things are affecting you, or how things will shake down...In some ways it's freeing...Then you feel guilty...Some of it is letting go. Letting go of the responsibility...of that [caregiver] role...it's letting go of that identity...it can be as simple as letting go of what was and what's no longer. (Marie)

Some SDCs conveyed this process through stories of change and grief. For these SDCs, the bereavement phase served as a time for dealing with and managing the changes to their everyday lives as well as the accompanying grief of losing their spouse. SDCs recognized these evolving processes related to change and grief as a significant and expected part of the bereavement phase.

What do I do now? What is my frame of reference? How do I program my days so that they are meaningful?...It's just hard to find a new pattern when, especially when (voice

trails off. pauses. starts crying) you were happy with the old one. (sniffles) The old one a long time ago. So, I don't know. Everything changes. I'm not good with change. (Nancy)

The grief is when, if you bring [Phil] up...I might get tearful, or I might feel a little catch. I've got it together. I'm able to manage. But it goes from that, crying a lot and thinking about it a lot, to just feeling the catch and, you know, to me that's all grief. It's phases of grief. (Emily)

Bereavement phase of the caregiver journey as a time of personal growth. SDCs described life after caregiving as a time for personal growth. Nancy articulated this time as shifting to be a “caregiver for yourself” and figuring out “who you are and who you want to be and what you want to do with your life.” She also indicated that “the caregiving period makes you appreciate what you have.” For SDCs in this study, the caregiver journey resulted in being more “patient” (Anna) and “compassionate” (Brenda). It also taught SDCs how to “not sweat the little things” (Susan). SDCs also revealed stories of resilience in their reflections on life after caregiving. Emily shared that “it did make me realize how far I’ve come,” and that she understood the bereavement phase of the caregiver journey as being about “finding yourself and finding your path.” Other SDCs also expressed personal growth through stories of introspection.

I did some heavy-duty introspection and prayer to heal myself. And that seemed to finally pull me through...I finally handed [the anger] over and it’s been better ever since...My faith is what finally got me through. (Jill)

SDCs shared stories of taking time to focus on themselves. For some SDCs, this meant going back to things that they did before their life was interrupted by dementia caregiving. This might also be a time when SDCs put their own needs and desires before the needs of others in their lives.

My son said, "Mom, you were just coming into your own, and Dad got sick." Well, my own thing was getting published with children's books. That was my goal. It's been my goal since I was in high school probably. But life kind of got in the way and I did- wasn't able to do it...I guess my own thing is being my own person. I've always been doing what somebody expected...I've always been what everyone else wanted. (Sherry)

Many SDCs shared stories of how having the time to focus on themselves allowed opportunities to learn and grow as a person. This was demonstrated through stories of learning and trying new things but also in overcoming fears and expressing new-found independence. This might also be expressed through reflections on how far SDCs felt they had come in facing the challenges of bereavement.

When I got this townhome there were a few things that needed to be done that required someone who had some skills. And I was petrified to do some of them...So, I would get out the hammer, I bought a drill, and I was so empowered...I'm doing things that I've never done before, by myself. (Susan)

It's like, you have been tested in a way. Although, caregiving is not a test, you don't get an A or B or whatever. You have been through this experience that shows you more who you are. So, I'm a lot less fearful...I am more open to trying new things...more open, more compassionate...I'm more willing to be vulnerable...to take a risk, to take a chance on myself. To better myself...you're forced to look at yourself. (Marie)

The relationships within the outcome space. Four qualitatively different categories comprise our outcome space: 1) the bereavement phase as an extension of caregiving, 2) the bereavement phase as moving on from caregiving, 3) the bereavement phase as an evolving process, and 4) the bereavement phase as a time for personal growth. Another significant element of the outcome space is the relationships among these categories. When we analyzed the outcome space, we found that all four conceptual categories were situated within everyday experience during the bereavement phase of the caregiver journey. This means that SDCs conceptualized their experience during the bereavement phase within the context of their everyday lives. Furthermore, each category had the potential to interact with the other categories of the outcome space and establish connections with components of everyday life. An example of these relationships is provided below.

We can get an idea of how the relationships within the outcome space might look by examining the following excerpt. This excerpt provides an account of how the categories of *the bereavement phase as an extension of caregiving* and *the bereavement phase as an evolving process* interact within the context of everyday life.

I really do think it's both. I think, the day that your loved one dies...there's not a line in the sand that, okay [the caregiver] role is finished. And, it does become part of who you are and changes how you look at the world...the experience changes you. And you're still incorporating that many years out. You're still incorporating what it was like to be a caregiver...And then, with my job, I also work with, I guess, share my time with other caregivers now in the support group that I facilitate and so it's like, that's another really important way that I carry on what I went through and use it for what I hope is to...make things better for other people...to give back in some way. (Marie)

Marie occupies two categories of the outcome space by explaining how she conceptualizes the caregiver role as continuing during bereavement and the process of change that is evolving over time. Her understanding of the caregiver role is interconnected with her understanding of the evolving process of change. She then situates these understandings within everyday experience by explaining how this relationship changes how she views the world and informs her role as a facilitator of a support group. As time passes, any of these components of the outcome space could shift in a way that would change the nature of this interactive relationship and potentially change her understandings of the bereavement phase.

The outcome space for this study can be described as one of dynamic and reciprocal relationships situated within the everyday lived experience of the bereavement phase of the caregiver journey. As Akerlind (2012) points out, “the structure of an outcome space need not always take the form of a linear hierarchy of inclusiveness” in phenomenography (p. 123). The reciprocal relationship structure of this study’s outcome space more accurately represents the dynamic nature of the SDCs’ conceptualizations of the bereavement phase of the caregiver

journey. It also allows for the real-life nonlinear experience of SDCs occupying multiple categories based on their evolving understandings of bereavement over time.

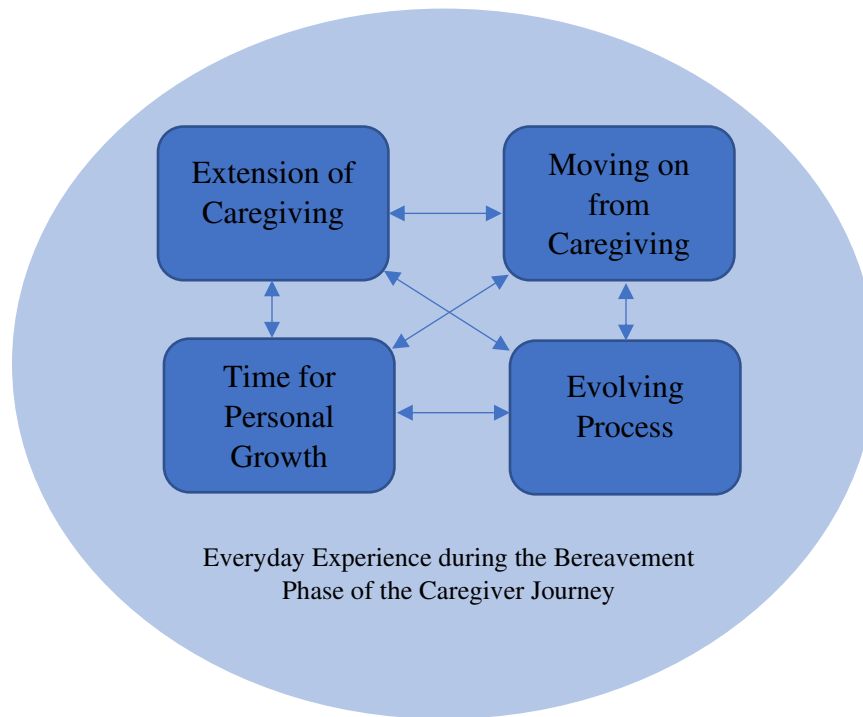


Figure 3.1

Outcome Space

Discussion

The concept of “the bereavement phase of the caregiver journey.” The aim of this study was to describe the collectively different ways SDCs experience the bereavement phase of the caregiver journey. The findings illustrate the dynamic nature of the ways SDCs conceptualize life after caregiving and how these understandings influence everyday life. All the SDCs in this study continued to identify with the caregiver role in some capacity following the death of their

spouse. This perspective aligns with literature indicating that the caregiver role does not immediately end with the death of the spouse receiving care. (Peacock et al., 2014). Rather, these SDCs continued to view their world in relation to their caregiving experience.

For some SDCs, life after caregiving served as an extension of the caregiver role in which caregiving was a valued trait or role that allowed them to strengthen relationships, share love, or give back to others. Another way of understanding the bereavement phase was as a period of moving away or distancing one's self from the caregiver role. For this category, the bereavement phase allowed SDCs opportunities to disengage from the role of caregiver and look forward to establishing new identities outside the context of caregiving. SDCs also viewed the bereavement phase as an evolving process that manifested in everyday experiences of change, grief, and letting go. The category of the bereavement phase as a time for personal growth displayed the SDCs' experiences related to their shift to focusing on themselves, learning new things, and reflecting on their caregiver journey. Again, SDCs often conceptualized their experience at any given time in more than one way. Each of these categories represent a different way SDCs conceptualized the experience of the bereavement phase within the context of their everyday lives.

Key features of the outcome space. Bereavement served as a turning point for the SDCs in this study. Our findings support the value of reflecting on turning points in interpreting past events and their meaning as well as preserving a sense of self and increasing awareness of personal growth (Hildon et al., 2008; Leonard & Burns, 2006). What our findings add to the literature is a conceptual context for how SDCs understand their experience following the turning point of bereavement. SDCs' conceptualizations of their experience during the bereavement phase illuminated the ways in which they adjusted to life after the death of their

spouse. SDCs in this study continued to adapt to life after active caregiving by framing their experience in action-oriented and forward-thinking ways. In many cases, these SDCs used everyday experiences such as watching a grandchild or volunteering in the community to facilitate this adjustment.

The interactions among the categories of the outcome space represent the dynamic nature of the SDCs' understandings of the bereavement phase. These categories also simultaneously interact with everyday experience resulting in multiple understandings of the bereavement phase. These findings align with the transactional understandings of everyday life that highlight the person-environment relationship as integral to understanding everyday experience (Cutchin, 2008). SDCs conceptualizations were continually influenced by their personal experiences, their environment, and additional contextual factors such as social supports and engagement in activities. These factors acted in a reciprocal manner that evolved over time.

Implications for practice. As occupational therapists and other health professionals strive to provide client-centered care to SDCs, it is important for us to meet SDCs where they are in terms of how they are feeling or thinking about their current situation. The need for health professionals to understand the experience of SDCs is true throughout the caregiver journey, including bereavement. One way to better understand the experience of the bereavement phase of the caregiver journey for SDCs is for therapists to understand the ways SDCs conceptualize life after caregiving. The current study used phenomenography to capture the qualitatively different ways SDCs conceptualize the bereavement phase experience. Using a phenomenographic approach allowed us to engage with the lived experience of these SDCs by viewing the variations in their experiences in a holistic way to increase our understanding of this experience (Akerlind, 2005). A better understanding of the lived experience of SDCs will provide the

opportunity for practitioners to provide more meaningful supports and services to SDCs during all phases of the caregiver journey, including bereavement. These SDC supports and services should include opportunities to interact with others and engage in activities in a way that considers the conceptual contexts of their experience during the bereavement phase.

This paper highlights an often-overlooked phase of the caregiver journey, bereavement. Increased knowledge of the bereavement phase provides practitioners with opportunities to engage with SDCs in a more informed way throughout the caregiver journey to meet their ever-changing needs. This work also illuminates a need for health professionals to advocate for the inclusion of SDC needs within dementia practice and for appropriate reimbursement options to provide therapy services and supports, including occupational therapy, to meet the health and well-being needs of SDCs throughout the caregiver journey, including bereavement.

Limitations and future directions. There are several limitations in this study. The majority of the SDCs in this study live in the same geographical area and are active in the same local caregiving community. Common SDC involvement in local supports and services may reinforce the homogeneous makeup of the study population. These similarities may decrease the degree of maximum variation achieved such as the experiences of SDCs that are more socially isolated or experiencing more extended periods of complicated grief (Bonanno, 2004). Furthermore, the caregivers that agreed to participate in this study were all women. While we recruited for both women and men, no men committed to participating in this research, potentially further limiting the level of variation found in our results. The absence of male participation in this study aligns with literature finding decreased participation and representation of men in caregiver research across health disciplines (Houde, 2002). Data collection began before the COVID-19 pandemic, which resulted in most of the interviews being conducted

remotely, during the pandemic. We have no clear way of knowing the extent to which this may have influenced our findings.

Additional research is warranted to examine the lived experience of the bereavement phase of the caregiver journey for a larger and more diverse sample of SDCs, including male caregivers. Current literature examining the male experience of dementia caregiving is limited and has yet to link the caregiving experience of men with their health and well-being throughout the caregiver journey (Robinson et al., 2014). Additional research is needed to examine the specific role occupation plays in understanding experience in the context of the caregiver journey, including bereavement for SDCs. Research is also needed to determine the most effective use of occupation as an intervention tool in everyday practice to address the needs of SDCs throughout the entire caregiver journey.

Conclusion

For this study, we used the voices of SDCs to illuminate the different ways they conceptualized the bereavement phase of their caregiver journey. These SDCs conceptualized bereavement in four different ways: as an extension of caregiving, as moving on from caregiving, as an evolving process, and as a time for personal growth. This set of four descriptive categories defined the outcome space of our study. Increased understanding of the ways SDCs conceptualize their experience during bereavement allows for more informed care to address the needs of SDCs throughout the entire caregiver journey, including the bereavement phase. This understanding can also inform direct occupational therapy services and meaningful referrals to additional community supports and services.

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CHAPTER 4: CONCLUSION

The findings from the phenomenological (Chapter 2) and the phenomenographical (Chapter 3) studies have elucidated the experience of spousal dementia caregivers (SDCs) during the bereavement phase of their caregiver journey. The aim of this dissertation research was to better understand resilience within the context of the bereavement phase of the caregiver journey. By examining the lived experience of SDCs during bereavement, this dissertation has enhanced our understandings of resilience and the role it plays following the loss of a spouse with dementia. This final chapter synthesizes the findings into three key takeaways, reflects on the research approach, provides recommendations, and situates this dissertation in Occupational Science and Rehabilitation Science.

Key Takeaways

The caregiver journey does not end when the person with dementia dies. In their work with dementia caregivers, Peacock et al. (2014) suggest that the caregiver journey does not immediately end when the person with dementia dies but, rather, their death begins the final stage of caregiving. This was true for all the participants in this dissertation. While not all the SDCs in these studies still currently identified with the caregiver role, they all reported still thinking of themselves as a caregiver for varied amounts of time after their spouse had passed away. For some SDCs, this was due to managing the details of their spouse's death such as completed paperwork and paying bills related to their care. For others, the role of caregiver left a more lasting impression on their everyday experience by shaping how they found meaning through engagement in activities such as volunteering to continue sharing their knowledge with other members of the caregiver community. Another salient feature for some of the SDCs was a

connection to the caregiver role as a part of their ongoing identity. For these SDCs, the caregiver role was a part of who they had always been, and they found satisfaction and purpose in their role as someone who took care of others.

Resilience is rooted in everyday experiences. The SDCs in this dissertation experienced resilience within the context of everyday life during the bereavement phase of the caregiver journey. SDCs shared stories reflecting resilience that were often interconnected with their everyday activities, relationships, roles, and routines. While discussing their experiences during the bereavement phase of the caregiver journey, the SDCs discussed challenges and supports to resilience as being directly connected to ordinary aspects of their everyday lives, such as calling a friend or sharing produce from their garden with the neighbors. These findings demonstrate the idea of resilience being “a social process arising from mundane practices of everyday life and situated in person-environment interactions” (Lenette et al., 2012, p. 637). The concept of resilience being rooted in everyday experience expands on this idea and draws attention to the everydayness of resilience during the bereavement phase of the caregiver journey.

One of the areas of everyday experience that proved to be especially helpful in supporting SDC resilience during the bereavement phase of the caregiver journey were connections to others. SDCs consistently and directly credited their social connections as supporting their ongoing resilience during bereavement. When compared with current literature, the value SDCs placed on their connections with others aligns with social factors found to facilitate resilience, such as being socially connected through positive relationships and having supportive emotional and social networks (Hildon et al., 2008; MacLeod et al., 2016). SDCs often discussed these connections with others within the context of another significant support to their resilience, engagement in everyday activities.

Engagement in meaningful activities was of utmost importance to the SDCs in these studies. The activities that SDCs expressed as being the most supportive of their resilience came in the form of activities, roles, and routines that provided structure and purpose to their everyday lives. From an occupational lens, most of these supports fall under the category of occupation in that they represented what these caregivers needed and wanted to do that gave meaning and purpose to their everyday lives. Hasselkus and Murray (2007) conceptualize everyday occupation as the “fabric of well-being” (p. 12). This certainly held true in the countless stories SDCs told of the everyday occupations that consistently supported their ongoing resilience and well-being such as baking, walking the dog, or babysitting a grandchild.

Conceptualizations of the bereavement phase of the caregiver journey demonstrate resilience. Bonanno (2004) asserts that spousal caregivers often experience bereavement from a place of resilience. This assertion became apparent when we examined SDCs’ conceptualizations of the experience of the bereavement phase of the caregiver journey. While their varied understandings of the bereavement phase produced a dynamic outcome space for SDCs in our second study, resilience emerged in two distinct ways. First, conversations that represented different conceptualization of the bereavement phase for SDCs contained stories that demonstrated resilience. These included experiences of feeling empowered by doing something new around the house or being able to reflect on the caregiver journey in positive ways that no longer focus on the loss. Second, the SDCs’ conceptualizations of the bereavement phase, themselves, demonstrated resilience. The ways SDCs in my studies understood their experience during the bereavement phase was action-oriented and forward-thinking in a way that both represented SDC resilience and supported their ongoing resilience.

Research Approach

This dissertation sought to deepen our understanding of the lived experience of SDCs during the bereavement phase of the caregiver journey. To capture this experience, I chose qualitative methods from a constructivist paradigm. This approach allowed me the opportunity to showcase the voices of SDCs and their stories throughout the construction of knowledge our findings provide. I used phenomenology to examine the experience of resilience in the everyday lives of SDCs. I then used phenomenography to further understand how SDCs conceptualized the bereavement phase of the caregiver journey and the role resilience played within these understandings of bereavement.

The use of phenomenology and phenomenography effectively addressed my dissertation aim of increasing understanding of resilience during the bereavement phase of the caregiver journey. This work focused on the experience of SDCs in enhancing this understanding of resilience. Phenomenology was chosen for the first study due to its strength in describing the “essence of a lived phenomenon” through the perspective of the individuals experiencing that phenomenon (Creswell & Poth, 2018, p. 104). This allowed the everyday lived experience of resilience by SDCs to be the focus in our findings. Phenomenography was chosen for the second study due to its ability to discern the qualitatively different ways a phenomenon, or the experience of a phenomenon, is conceptualized or understood by a group of people (Marton, 1994; Marton & Booth, 1997). This approach was important in taking a step back in our discussion of resilience to take a closer look at the ways SDCs conceptualized the experience of the bereavement phase of the caregiver journey. This examination produced an outcome space of our findings that described the relationships between the varied ways SDCs understood the bereavement phase of the caregiver journey (Akerlind, 2012). This process informed a deeper

understanding of the context in which resilience was experienced by these SDCs during the bereavement phase of the caregiver journey. Together, these qualitative approaches provided the methods needed to appropriately address my research aims in a way that aligns with my theoretical framework.

The methods used in my studies reflect the constructivist theoretical framework I used for this dissertation. By using the experience of losing a spouse to dementia as a turning point for SDCs, I situated our examination of resilience within the bereavement phase of the caregiver journey. My qualitative approach assisted in demonstrating the dynamic nature of resilience over time, along the life course and within the context of aging for the SDCs in my studies. This approach also highlighted the nested characteristics of SDCs, their families, and their communities found when viewing resilience from an ecological perspective (Aldwin & Igarashi, 2012). A key component of this work was telling the story of resilience through the voices of the SDCs themselves. The bereavement phase of the caregiver journey provides a significant life experience that SDCs story their lives around. These narratives play an important role in telling a story that enables opportunities for resilience through learning, growth, and wisdom (Nelson-Becker, 2013). And within these stories, a deeper understanding of resilience emerges.

Recommendations

Given the current literature addressing resilience and the findings of this dissertation, I have a few recommendations for future work addressing resilience and the bereavement phase of the caregiver journey. First, it is necessary to include the voices of caregivers in research related to resilience to enhance our understandings of how resilience functions in everyday life during the caregiver journey. These understandings can work to inform more effective and meaningful caregiver supports and services. Second, it is important to understand the role of occupation in

supporting resilience throughout the caregiver journey, including the bereavement phase. Occupation served as both a means of facilitating resilience and as the outcome of resilience for SDCs during the bereavement phase of the caregiver journey. Further research is warranted to identify and develop interventions that effectively and deliberately use occupation to foster resilience throughout the caregiver journey. Lastly, occupational therapists need to be more involved throughout the caregiver journey to address the needs of both members of the caregiving dyad. Dementia caregivers, especially SDCs, should be considered prominent members of the client constellation with acknowledgment of their personal health and well-being needs. Focus on the health and well-being needs of the caregiver should carry over into the bereavement phase of the caregiver journey. Further research is needed to determine effective ways to incorporate caregiver needs into daily practice in ways that address health and well-being while supporting resilience throughout the caregiver journey.

Occupational Science and Rehabilitation Science

This dissertation work is grounded in a multi-disciplinary approach. A significant portion of my current understanding and conceptualization of resilience comes from the fields of psychology, social work, gerontology, and nursing. Each of these fields greatly contribute not only to the overall body of resilience research in the contexts of aging and caregiving but also to the theories, perspectives, and models highlighted in the literature reviews found in my studies. In addition to the contributions of the research of these fields to my dissertation work, I also am strongly influenced by Occupational Science and Rehabilitation Science.

Occupational Science (OS) substantially contributes to my dissertation work through conceptualizations of occupation and approaches to understanding human experience. OS is the study of the human as an occupational being (Clark et al., 1991; Yerxa, 2000). Not only do

humans have a biological need for occupation but, also, what occupational beings do and how they do it impacts their health and well-being (Clark, 1997). OS focuses on the multidimensional nature of occupation, seeking to go beyond simply explaining what people do but also examining the reasons and causes of why people do the things they do (Clark et al., 1991). Occupations are contextual, transactional, dynamic, and fluid (Dickie et al., 2006). OS also emphasizes the “ability of humans throughout the life span to actively pursue and orchestrate occupations” (Clark et al., 1991, p. 300). Further, Christiansen (1999) highlights the importance of occupation in creating meaning, purpose, sense of self, and identity. These elements of occupation and OS are represented in the occupational lens I used to view and understand the findings in my studies. Occupation provides the means by which individuals adapt to changing needs and conditions (Schultz & Schkade, 1992). Frank (1996) offered an occupational science definition of adaptation as “a process of selecting and organizing occupations to improve life opportunities and enhance quality of life according to the experience of individuals or groups in an ever-changing environment” (p. 50). This dynamic person-environment relationship also is a key feature of Rehabilitation Science.

The prominent feature of Rehabilitation Science (RS) that influences my dissertation work in resilience is the concept of the enabling-disabling process. RS is the study of transitions among states in the enabling-disabling process focusing on the restoration of functional capacities in a person and the interaction of that person with the surrounding environment (Brandt & Pope, 1997). The RS concept of the enabling-disabling process posits that health and functioning exist on a continuum and are influenced by an interaction between the person and contextual factors. The enabling-disabling process is used “to help clarify the fact that disability is not inherent in the individual, but rather is a product of the interaction of the individual with

the environment” (Brandt & Pope, 1997, p. 8). This approach grounds disability much more soundly in the realm of the interaction with the environment. According to Brandt and Pope (1997), the enabling process consists of environmental medication and/or functional restorations and the disabling process consists of four major components: pathology, impairment, functional limitation, and disability. These conceptual ideas align well with the concepts related to the risk/vulnerabilities and protective factor components of resilience that present contextual factors as interacting to either facilitate or hinder resilience (Donnellan et al., 2015; Hildon et al., 2008; Nelson-Becker, 2013).

Concepts related to OS and RS were evident throughout both studies. The most prevalent of these concepts were the dynamic person-environment relationship and the idea that health and functioning exist on a continuum that is influenced by contextual factors. The SDCs in these studies acknowledged the constant influence the environment had on challenging or supporting their resilience throughout the bereavement phase of the caregiver journey. Physical environments such as one’s home may produce feelings of sadness and loneliness that challenge resilience, or it may represent strength, courage, and positive change to support an SDC’s resilience. As mentioned above, having positive social environments substantially supported resilience by providing opportunities for SDCs to engage in valued social connections. This constant interaction with their environment was reported as being an evolving process. SDCs frequently spoke of their abilities to manage the everyday challenges of bereavement in a way that reflected the ever-changing nature of resilience over time within the context of everyday life. They also directly conceptualized resilience and well-being as being a continual process situated along a continuum that resulted in constant change. The knowledge gained from this dissertation

regarding resilience within the context of the bereavement phase of the caregiver journey fit nicely within OS and RS frameworks.

Concluding Remarks

By examining the experience of spousal dementia caregivers during the bereavement phase of the caregiver journey, this dissertation provides valuable insights into the experience of resilience within the larger context of aging. Given the aging population and the growing number of dementia caregivers, it is crucial for resilience research to include the experiences of spousal dementia caregivers. It also is important to address the needs of caregivers and promote their resilience throughout the entire caregiver journey, including the bereavement phase. This dissertation begins to fill the current gaps in research regarding resilience and caregiving that often exclude the bereavement experience of the caregiver journey. This work moves research forward by using an occupational lens not only to further our understandings of resilience and the bereavement phase of the caregiver journey, but also to highlight the role of everyday occupation in supporting resilience.

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