THE MENTAL HEALTH NEEDS OF

CORESIDENT OFFSPRING DEMENTIA CAREGIVERS:

AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS

by

Nancy L. Cadwell Dusthimer

Liberty University

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Philosophy

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ABSTRACT

This interpretative phenomenological analysis was conducted to deepen understanding of the experience of six daughters who cared for and lived with a mother with dementia. Caregivers for a loved one with dementia experience well-documented stressors, but less is known specific to offspring who care for a parent with dementia, particularly related to their mental health needs and potential means of addressing those needs. Because family caregiving is grounded within the family system, the study utilized a systemic lens, also considering the formal caregiving and societal systems. With the exception of some benefit from paid services of adult day care or in-home care, the formal caregiving and societal systems were largely absent or not supportive in these caregivers' stories. Findings supported the significance of a caregiver's family of origin as an exacerbator or revealer of family dynamics in parent care, potentially opening unresolved conflicts or providing opportunities to find resolution. Other findings were that trust is salient to forming a caregiving team with or without one's siblings; that caregiving challenges a caregiver's identity; that dementia caregiving entails loss and, in maternal dementia care, there is loss of mother as mother; that in the stresses of dementia caregiving are positives and growth opportunities; and that finding and making meaning are important in coping with caregiving. Identified mental health needs, shaped by the role of dialectics in dementia caregiving, were for thriving, cognitive flexibility, hope, relief from family conflict, respite, and autonomy. Beneficial mental health services suggested by the findings emphasize working from a family systems lens; awareness of identity development and potential loss of self, the importance of meaning-making, the need for hope, and the threats to autonomy in caregiving; and consideration of dialectical behavior therapy skills training. The latter emerged from findings of ambiguities and dialectics experienced by the caregivers and the potential for benefit from greater

dichotomous thinking. Areas recommended for further research include the family system in offspring parent care, expansion of previous studies looking at ambiguous loss in dementia caregiving, the mental health needs of understudied caregivers, the potential of dialectical behavior therapy skills training for offspring dementia caregivers, and examination of findings that hint at a phenomenon of reverse attachment in dementia parent care.

Keywords: dementia, caregiver, caregiver stress, caregiver burden, offspring, dyadic relationship, meaning-making

Dedication

This is first dedicated to the six women who shared honestly and without sugarcoating, their exemplary love and service to their mothers. The clear pictures you provided of a valuable and challenging life experience will inspire and encourage others in the trenches. It is secondly dedicated to those others, caregivers for people whom they love and are gradually losing. It is noble and courageous work you do.

I also want to dedicate my work to those in my life who have taught me how to be a caregiver, albeit not so intensely as the women in this study:

The late Walter and Gladys Cadwell, my paternal grandparents

The late Martha Cadwell, my precious mother

Reverend Henry Cadwell, who with my mother dedicated his life to the spiritual care of others

Ina Mae Cadwell, my dear aunt

Will Horosz, Victoria Skaggs, and Peter Horosz, who taught me how to care as a mother

Finally, there have been many in my life who taught me how to love and honor the aged. That includes my late maternal grandparents, Frank and Edith Hutchins, and the many souls who touched my life over 22 years of working in the field of aging, specifically Inez, Audrey, Agnes, Gussie, Lillian, Jim, and June.

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AARP Public Policy Institute (AARP-PPI)

Activities of daily living (ADLs)

Alzheimer's disease (AD)

Alzheimer's Disease International (ADI)

Alzheimer's Association (AA)

Alzheimer's Society (AS)

American Counseling Association (ACA)

American Psychiatric Association (APA)

Area Agencies on Aging (AAA)

Behavioral Risk Factor Surveillance System (BRFSS)

The Bowen Center for the Study of the Family (BCFS)

Building Our Largest Dementia Infrastructure for Alzheimer's Act (BOLD)

Caregiver (CG)

Care recipient (CR)

Centers for Disease Control and Prevention (CDC)

Central Ohio Area Agency on Aging (COAAA)

Dementia caregiver burden (CGB)

Dementia Care Network (DCN)

Dialectical behavior therapy (DBT)

Differentiation of self (DoS)

Family Caregiver Alliance (FCA)

Family of origin (FoO)

Finding Meaning Through Caregiving Scale (FMTC)

Instrumental activities of daily living (IADLs)

Interpretative phenomenological analysis (IPA)

Lifespan Sibling Relationship Scale (LSRS)

Miami University Scripps Gerontology Center (MU)

National Alliance for Caregiving (NAC)

National Alzheimer's Project Act of 2011 (NAPA)

National Association of Area Agencies on Aging (n4a)

New York University Caregiver Intervention (NYUCI)

Parental Bonding Instrument (PBI)

Patient Health Questionnaire-9 (PHQ-9)

Persons with dementia (PWD)

Positive psychotherapy (PPT)

Primary care physician (PCP)

Randomized control trials (RCT)

Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017 (RAISE)

Resources for Enhancing Alzheimer's Caregiver Health (REACH)

Revised Memory and Behavior Problems Checklist (RMBC)

Sense of coherence (SOC)

World Health Organization (WHO)

Zarit Burden Interview (ZBI)

CHAPTER ONE: INTRODUCTION

The Problem and the Need for This Study

Mental health counseling for caregivers (CGs) of persons with dementia (PWDs) is understudied, hard to access, and seldom offered to stressed CGs (Family Caregiver Alliance [FCA], 2016). It is well established that CGs often have negative mental health outcomes from the stressors of caregiving (Cannuscio et al., 2002; Hajek & König, 2016; Thomas, Saunders, Roland, & Paddison, 2015), particularly dementia caregiving (Riedel, Klotsche, & Wittchen, 2016; van der Lee, Bakker, Duivenvoorden, & Dröes, 2014; Wolff, Spillman, Freedman, & Kasper, 2016). Less is known about rewards of caregiving, what differentiates CGs with negative outcomes from those who fare better, the impact of caregiving transitions, differential mental health needs of offspring versus spouse CGs, and the impact of coresidency with the care recipient (CR). Nor is it understood why offspring CGs were largely unwilling to participate in the family counseling module of an empirically supported treatment that was first studied with spouse CGs (Gaugler, Reese, & Mittelman, 2015). This study intends to deepen understanding of the mental health needs of offspring CGs to PWDs in order to better address those needs.

Problem Statement

The populations of the US and of the world are aging rapidly (He, Goodkind, & Kowal, 2016) and the relative number of persons available to function as informal CGs is decreasing, leading to a declining CG-CR ratio (Redfoot, Feinberg, & Houser, 2013; Schulz & Eden, 2016). As the population over the age of 75 increases most rapidly, many CGs will themselves become CRs (He et al., 2016), potentially further lowering the CG-CR ratio. Between 2010 and 2030 persons in the prime caregiving years (45–64) will increase by 1%, while those in the prime CR years (over 80) will increase 79%, resulting in a 43% decline in the ratio of CGs to CRs (Redfoot

et al., 2013). Fewer CGs providing care to more CRs will likely lead to financial burdens to

families and to society and emotional and physical burdens to CGs (Redfoot et al., 2013).

Commensurate with the aging population is a rapid increase in the prevalence of persons

with Alzheimer's disease (AD) and other dementias. Unless new treatments can cure or slow the

progression of AD, the 2015 estimate of 5.1 million persons with AD in the US will increase

greater than 2.5 times to 13.5 million by 2050 and the number of persons living in the severe

stage of AD, requiring the greatest amount of care, will nearly triple to 6.5 million (Alzheimer's

Association [AA], 2016b). Globally, the incidence of dementia is expected to rise rapidly,

doubling every 20 years and even more quickly in Asia, Africa, and Latin America (World

Health Organization [WHO], 2015a). Notably, the rate of dementia may be underestimated

(Ikejima et al., 2012).

Support for PWDs and their CGs is an urgent international health priority, requiring

efforts to find a cure and to improve the quality of life for dementia CGs and CRs (WHO,

2015b). Considering the statistical evidence that CGs will be increasingly in demand and the

impending "tidal wave of dementia" (WHO, 2015a, p. 9), until a cure is found, addressing CG

and CR quality of life issues is crucial. The need to change and improve attitudes, knowledge,

and services related to dementia can best be accomplished if the voices of those with dementia

and their CGs are instrumental in shaping such changes and improvements (WHO &

Alzheimer's Disease International [ADI], 2012). Early in the disease process, PWDs can still

tell their stories and express their needs (Munro, 2015) and when they are no longer able to share

their own voices, CGs can give them voice (Picker Institute Europe, 2016). CGs, who can offer

a depth of insight that formal providers may lack (WHO & ADI, 2012), are not routinely

included in policy deliberations or even care decisions (Schulz & Eden, 2016).

The caregiving experience does not always differ greatly based on the disease process necessitating care (Wuest & Hodgins, 2011) and there is a call for more cross-diagnostic caregiving research (Singer, Biegel, & Ethridge, 2009). However, diagnosis-specific research is still needed (Savundranayagam, Montgomery, & Kosloski, 2011). Dementia CGs appraise the caregiving experience differently than nondementia CGs, and dementia caregiver burden (CGB) differs qualitatively and quantitatively from nondementia CGB (Bertrand, Fredman, & Saczynski, 2006; Pinquart & Sorensen, 2003). This study focuses only on dementia CGs for whom there is potential to have high objective and subjective burden particularly related to CR behaviors (Pinquart & Sorensen, 2003; Shim, Kang, Kim, & Kim, 2016; Vaingankar et al., 2016; van der Lee et al., 2014; Wolfs et al., 2012). A homogenous participant group is recommended in the chosen methodology of interpretative phenomenological analysis (Smith, Flowers, & Larkin, 2009). Such a specific focus does not negate the importance of CG research to promote advocacy and policy development cross-diagnostically (Singer et al., 2009). It is hoped that the findings from the current study add to a knowledge base that can clarify which CG supports are specific to CR condition and which can be developed for all CG-CR dyads.

That CGs have unmet mental health needs is well-established in the literature (Alwin, Öberg, & Krevers, 2010; Charlesworth et al., 2008; Lévesque al., 2010; Thorpe, Van Houtven, & Sleath, 2009) although understanding is lacking regarding the complexity of the needs, mental health CG assessment (Lévesque et al., 2010), and how to shape mental health supports. There is evidence that the cognitive appraisal of the caregiving situation is associated with the level of perceived CG stress (Bertrand et al., 2006), that problem-focused coping is more effective than emotion-focused coping (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007), and that meaning-making in the caregiving situation can improve CG mental health (McLennon,

Habermann, & Rice, 2011) and other outcomes (Quinn, Clare, McGuinness, & Woods, 2012). Meaning-making may be important not only related to the caregiving journey, but also to decisions CGs make along the journey (Farran, 1997; Peacock, Hammond-Collins, & Forbes, 2014). For CGs in a transitional stage of caregiving, specific interventions (Coon & Evans, 2009) and more insight are needed to enhance adaptation and coping (Gibbons, Ross, & Bevans, 2014). Coon and Evans (2009) identified placement of the CR in formal care and death of the CR as caregiving transitions, but it can also include changes in who is doing the caregiving, commencing coresidence, and other changes that may demand adaptation and coping skills. Multicomponent therapies (Belle et al., 2006; Coon & Evans, 2009; Mittelman, Epstein, & Pierzchala, 2003) and ones that address cognitive appraisal (Mittelman, Roth, Haley, & Zarit, 2004), existential issues of meaning (Stöckle, Haarmann-Doetkotte, Bausewein, & Fegg, 2016), and problem-solving (Chiu, Pauley, Wesson, & Pushpakumar, 2015) may be beneficial, but little is known regarding relative efficacy or which types of CGs might benefit (Spijkew et al., 2008).

It is imperative that research address this lack of knowledge considering the noted decline in CG-CR ratio, especially for PWDs. The data suggest the potential informal CG shortage may be most severe for PWDs and those are the very CGs with greater risk of negative mental health outcomes (Bertrand et al., 2006; Pinquart & Sorensen, 2003). To reduce this risk and provide greater opportunities for caregiving rewards, researchers must listen to CGs' own accounts of the experience of dementia caregiving, how the CGs find meaning in the experience, and what barriers they encounter to meaning-making and to mental well-being. Chapter Two will provide delineation of the existing knowledge base of CG mental health and treatment.

Purpose of the Study

The current study contributes to the knowledge base by amplifying the voices of a group

of coresident offspring CGs of a PWD. In the literature, finding meaning in caregiving is associated with more rewards and better mental health outcomes. This research sought to elicit CGs' reflections on their experience and meanings, within the following conceptual framework.

Research Questions

This study's primary research question was, "What are the mental health needs experienced by coresident offspring caregivers of a parent with dementia?" As per Smith and Shinebourne (2012), the subquestions are descriptive, reflective, and idiographically detail-focused:

1. How do the caregiver participants describe their caregiving experience?

2. In what ways does the caregiving phenomenon interface with the caregivers' experience of:

   a.   the societal, caregiving, and family systems

   b.   the relationships with the care recipients

   c.   the relationships with the caregivers' sibling(s)

   d.   the caregivers' sense of identity

3. How do the caregivers understand and make sense of the caregiving experience?

4. How do the caregivers' experiences differ from each other and in what ways are they similar?

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Conceptual Framework

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Clear explication of the theoretical underpinnings of caregiving research is necessary for understanding and effectively applying the results, informing public policy (Roberto & Jarrott, 2014), and guiding interventions (Petriwskyj, Parker, O'Dwyer, Moyle, & Nucifora, 2016) in a rapidly changing field of inquiry (Talley & Travis, 2014). This research derives its impetus from belief in the value of CGs and utilizes a systemic lens with leanings toward existential and positive psychologies, considering influential factors from caregiving research.

The decency of a society is shown in how it treats those who are old, permanently disabled, or dependent on others (Heschel, 1975; WHO, 2015a). Thus, a just society will value those persons' CGs, whose well-being is closely tied to the CRs and who advocate for CRs (Galvin, Todres, & Richardson, 2005). CGs are invaluable (Reinhard, Feinberg, Choula, & Houser, 2015) members of the CR care team (Zarit, 2004), indispensable for CR welfare (Schulz & Eden, 2016), and the backbone of elder services (Redfoot et al., 2013). Their emotional needs must be assessed and addressed (Zarit, 2004). CGs carry out their role in interdependent societal, caregiving, and family systems, which can interact in supportive or obstructive ways (Carpentier, Ducharme, Kergoat, & Bergman, 2008). The current study's conceptual framework has a particular focus on the family system, the immediate caregiving milieu. CG outcomes are related to the quality of family relationships (Henretta, Soldo, & Van Voorhis, 2011; Mahoney, Regan, Katona, & Livingston, 2005; Steadman, Tremont, & Duncan Davis, 2007), satisfaction with the family situation (Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2014), and level of family support (Pi-Ming, Wierenga, & Yuan, 2009).

The Societal System

Caregiving can precipitate loss of social connection, and CGs have reported unhelpful and even obstructive community encounters (Frankowska & Wiechula, 2011; Galvin et al., 2005). Thus, the society that needs CGs may feel inaccessible and unsupportive to them. Society's need for CGs noted above can become a source of increased burden to CGs by superimposing meaning onto caregiving that is not of existential import to particular CGs (Levine et al., 1984). Societal changes such as increased mobility, women choosing to stay in the work force, more step and blended families, complicate caregiving and provide an opportunity to renegotiate societal expectations of families to provide the bulk of care. A healthy

interdependence on the societal system can be beneficial to CGs, CRs, family, and society

(Sanborn & Bould, 1991). Meanwhile CGs often feel that keeping their loved one home is the

normative and natural thing to do (Hodgetts, Pullman, & Goto, 2003; Wuest, Malcolm, &

Merritt-Gray, 2010) and this expectation, which influences CG outcomes, is culturally shaped

(Kosloski, Young, & Montgomery, 1999; Pharr, Francis, Terry, & Clark, 2014; Pinquart &

Sorensen, 2005).

The Caregiving System

Medical and service providers may generate barriers to CG support (Carpentier et al.,

2008). There is legislation to include CGs in care planning for hospitalized CRs (Coleman,

2016) and a call for more collaboration with CGs by their professional counterparts with focus

on validation, recognition, empowerment, partnership, and respect, and de-emphasis on CGs as

care resources (Lévesque et al., 2010). For example, the Canadian professional home care

system has relied on CGs without recognizing their need for support (Martin-Matthews, Sims-

Gould, & Tong, 2013). CRs' physicians have underestimated CG depression symptoms and

needs (Riedel et al., 2016). These physicians' primary task is CR health but partnering with CGs

would promote CR health (Riedel et al., 2016). That CGs sometimes must advocate for CRs to

obtain services (Galvin et al., 2005) suggests the caregiving system lacks partnership.

The Family System

Family systems theory asserts that individuals are interdependent members of family

systems (Keeling, Dolbin-MacNab, Hudgins, & Ford, 2008). In turn, the family system exists

within social, political, religious, and other systems with which it is interdependent (). How a

family adapts to the altered roles and challenges to its structure caused by caregiving can

increase cohesion and have positive effects on the family system (Sanborn & Bould, 1991).

Family systems are multigenerational, and, while their structure may change greatly over time, individuals continue to be influenced by the dynamics of the family system (Kerr, 2010). This is reflected in offspring CGs whose attribution of distress to the caregiving role is influenced by the degree to which they recall a positive, caring parental bond in their formative years (Daire, 2004). Thus, the caregiving dyad does not function in relational or chronological isolation. Rather, the systems of which it is and has been a part influence CR, CG, and their interactions. Preexisting unresolved family conflict can complicate caregiving (Keeling et al., 2008). To provide a framework for understanding these complexities this research views the caregiving dyad through a Bowenian family systems perspective.

Bowenian family systems theory. Because caregiving as addressed in this study occurs in a family context, it is of value to consider the mutual impacts of the family system and the caregiving experience. Bowenian family systems theory asserts that the members of a family are interdependent such that changes in behaviors and emotions in one member cause reciprocal change in the other member(s) (The Bowen Center for the Study of the Family [BCFS], 2016h). Stress within the family unit disrupts the system and can lead to disproportionate emotional burden on one family member whose attempts to accommodate the tension in the system may lead to feelings of isolation, being overwhelmed and loss of control (BCFS, 2016h), experiences that are common in CGs (AARP Public Policy Institute [AARP-PPI] & National Alliance for Caregiving [NAC], 2015b; Lopez, Lopez-Arrieta, & Crespo, 2005; Reinhard et al., 2015). Notably, resilience factors for CGs of social connection (Schuz et al., 2015), self-efficacy, and mastery (Harmell, Chattillion, Roepke, & Mausbach, 2011), are also antidotes to isolation, feeling overwhelmed, and loss of control. Bowenian theory also speaks of intergenerational transmission of emotional and behavioral patterns (Bowen, 1966; Johnson, 2010). Apprehending

the emotional systems in which an individual lives, particularly the family system, is important

for understanding and problem resolution (BCFS, 2016h), including for dementia CGs. Bowen

family systems theory and its eight basic concepts provide a framework for that understanding.

Triangles. In Bowenian theory a three-person system is considered the "basic building

block" (Bowen, 1966, p. 356) of the family system. Dyads cannot sustain stress without

bringing in a third person (BCFS, 2016i). In a two-parent household, in addition to potential

triangles of two parents and each offspring, there are often multiple interlocking triangles

(Titelman, 2003). It is likely that the original triangle of an offspring CG (BCFS, 2016i)

includes the current CR and that the stresses of caregiving (Kenny, King, & Hall, 2014; Riedel et

al., 2016; Thomas et al., 2015) will alter the dynamics of existing triangles of the CG (BCFS,

2016i). Tension is likely to spread to interlocking triangles (BCFS, 2016i) such as CG, CG

spouse, and their child. New triangles that include the caregiving dyad may also be formed with

spouse, siblings of the CG, members of professional support systems, or others. Some of the

possibilities for triangulation related to caregiving are illustrated in Figure 1.

Differentiation of self. Bowenian theory asserts that the self develops and individuates in

relation to others in the family of origin (FoO), shaping one's expectations of others and the

capacities to handle conflict with an intact self, to make rational decisions, and to adapt to stress

(BCFS, 2016a). Poor differentiation is evidenced when individuals, not seeing themselves as

discrete, are easily influenced by what others think or say, or exert inappropriate control over

others (BCFS, 2016a). Those with low levels of differentiation tend to react to anxiety

producing situations, particularly relational situations, with little rational thought and are driven

to relieve uncomfortable feelings (Bowen, 1966); whereas higher levels of differentiation of self

(DoS) entail simultaneous capacities to emotionally connect with another and to be autonomous

in managing one's own emotions (Kerr & Bowen, 1988). The ability to adapt to stressors is indicative of one's degree of differentiation (Smith, 2013).

It is intuitive that caring for one's parent, a primary FoO figure, might magnify unresolved DoS and that adaptation to stress, rational decision-making, and not being easily controlled by or needing to control others would contribute to a more positive caregiving experience. Indeed, self-esteem of daughter CGs is associated with strain in the relationship with the parent and, when the role of daughter is important to the CG, her self-esteem is associated with emotional closeness to the parent (Li & Seltzer, 2005). It is unclear if these correlations relate to relationship strain and closeness dating to the FoO system, but other research found that perceptions of the past relationship with a parent are associated with current CGB for daughter CGs (Coletti, 1997). While attachment, formed in childhood relationships with parental figures, is not a Bowenian concept, there is research that finds some convergence of the constructs of attachment and DoS (Skowron & Dendy, 2004). Additionally, high DoS bears a similarity to secure attachment (Ross, Hinshaw, & Murdock, 2016). Both constructs were related to self-regulation and the capacity to manage strong emotions, particularly in relationships (Skowron & Dendy, 2004). Thus, research that reflects adult attachment may be relevant to the discussion of DoS for offspring CGs. Adult attachment predicted the stability of an individual's self-esteem (Foster, Kernis, & Goldman, 2007) and was associated with personality traits only in the context of interacting with parents in adulthood (Robinson, Wright, & Kendall, 2011). Together these findings support the association of relationship with a parent, who for offspring CGs is the CR, to the capacity to develop an autonomous sense of self, self-esteem, adult personality, and CGB.

Nuclear family emotional system. Bowenian theory asserts that the emotional system in the FoO shapes basic interactional patterns that children carry forward into their own families

and relationships (BCFS, 2016e). Marital conflict, dysfunction in a spouse or in one or more

children, and emotional distance are the patterns that occur in response to stress upon the system.

In a qualitative analysis, emotional distance, one factor in a measure of the quality of CG family

dynamics (Kusaba et al., 2014), seemed to result from CG regrets that they were not fulfilling

their duties and emotional connection was the reciprocal of task fulfillment (Chan et al., 2012).

The occurrence of disrupted and sometimes dysfunctional relationship patterns in families

seeking therapy for caregiving problems prompted the development of systemic caregiver family

therapy (Qualls & Williams, 2013), supporting the notion that CG problems may have relational

antecedents and sustainers (Keeling et al., 2008).

   Family projection. Parents' tendencies to project their own emotional difficulties and

undifferentiation onto their children (BCFS, 2016c) is apropos to the family CG system. If the

parent needing care was not well differentiated, interpersonal sensitivities may have been

projected onto the offspring giving care or another sibling, potentially complicating caregiving

dynamics. Those dynamics relate to need for approval, self or other blame, misplaced locus of

control for one's own or others happiness, and hypersensitivity to the demands of others (BCFS,

2016c). For example, a mother who believed she was responsible for her children's happiness,

may have projected this onto a child who, now as the CG, feels responsible for the mother's

happiness, increasing the emotional burden of caregiving. There appears to be a correlation

between negative emotional health in CGs and their perception of expectations to care (Kosloski

et al., 1999) or lack of choice in caregiving (Schulz & Eden, 2016). CG stress occurs in an

inherently incongruous relationship (Llanque, Savage, Rosenburg, & Caserta, 2016) and, when

the CR has dementia, there may be reduced opportunities to receive approval, induce happiness

in the CR, or obtain clarity regarding expectations (Skaff & Pearlin, 1992).

Sibling position. The position of a child in the FoO influences the degree to which that child develops leadership tendencies and experiences expectations to assume responsibility (BCFS, 2016f). Research demonstrates a correlation of sibling position to the expectations elderly mothers have of their children (Suitor & Pillemer, 2007). Expectation of caregiving based on sibling position appears to be culturally specific (Pharr et al., 2014). Sibling rivalries and proving oneself the better offspring have been noted to be a primary source of conflict in families dealing with parental dementia (Peisah, Brodaty, & Quadrio, 2006; Williams et al., 2016). The ways that sibling position influences the choice of caregiving roles, may give offspring insights into the role of sibling position in the FoO (Hogstel, Curry, & Walker, 2005).

Multigenerational transmission process. Bowen (1966) asserted that the degree of differentiation in parents influences their children's DoS, creating a pattern across generations (BCFS, 2016d). Such multigenerational transmission may affect the specific caregiving expectations related to the roles of the CR's offspring, the CG's capacity to care without enmeshment, and the family system's understanding of elder caregiving as it occurred in past generations. A successful CG intervention incorporated all the CR's offspring in family counseling sessions (Mittelman et al., 2003), yet when the CG was one of the offspring there was strong resistance to family sessions (Gaugler, Reese, & Mittelman, 2013). That offspring resisted family therapy could be related to CG reports that dementia caregiving decreased family cohesion and altered interconnectedness in the family (Välimäki, Vehviläinen-Julkunen, Pietilä, & Koivisto, 2012). In turn, changes to cohesion and connectedness in the family may influence DoS for family members engaged in the inherently mutigenerational experience of parent care. Thus, Bowenian multigenerational transmission process may be of import in dementia care.

Emotional cutoff. Emotional cutoff (Titelman, 2003) occurs when family members

reduce or end actual or emotional interaction with others in the FoO to avoid unresolved conflict (BCFS, 2016b). The cutoff typically occurs between generations and may occur cyclically with episodes of fusion fed by poor DoS (Titelman, 2003). Cutoff is reflective of unresolved parental attachment and immature separation and individuation and it is thought to exacerbate family conflict in the long run, interfere with differentiation, and reduce coping capacity (Titelman, 2003). People typically experience some unresolved FoO attachment issues influenced by the degree of individuation of the family members (BCFS, 2016b) that occur within an emotional relational continuum from open to cutoff (Titelman, 2003). Establishing one-to-one relationships with members of one's FoO, particularly when there is a significant family transition, serves as a bridge to resolve cutoff and support personal development and individuation (Titelman, 2003). The initiation or increase in intensity of offspring caregiving has the potential to reignite problems that emotional cutoff made dormant but did not resolve, or it can also be a bridge to overcome emotional cutoff (Jacobs, 2015; Wuest et al., 2010).

     ***Societal emotional process*.** Emotional cutoff and the other six principles of Bowenian theory occur on a societal level, paralleling the family system (BCFS, 2016g). As in the family system, the appropriate level of societal togetherness is linked to healthy differentiation of the members of the system. In anxious social times, undifferentiated leaders and systems tend to act out of anxious reactivity rather than on principles and long-term goals (BCFS, 2016g; Friedman, 2007). A growing source of chronic social anxiety is the decreasing CG-CR ratio and increase in numbers of PWDs. Subsystems that care for the weak are a reflection of a society's level of differentiation (Baker, 2003) and, in the US, the caregiving system is fragmented (Feinberg & Levine, 2015). Thus, CGs, essential members of that subsystem, must navigate the interactive, complex dynamics of family and societal systems (Peluso, Watts, & Parsons, 2013), both of

which may be unsupportive or even a hindrance to the CG (DiZazzo-Miller, Pociask, & Samuel, 2013). The caregiving role has historically been given short shrift in the public sphere (Keady, Ashcroft-Simpson, Halligan, & Williams, 2007), and caregivers may experience lack of appreciation (Feinberg, 2014b) and visibility, isolation, and insufficient support and guidance, a scenario especially challenging to less differentiated CGs (Reinhard, Feinberg, & Choula, 2012).

   ***Summary of the application of Bowenian family systems theory to caregivers*.** In a society and in a family, a healthy level of differentiation enhances the capacity to concern one's self with the well-being of others (Kerr & Bowen, 1988). Caregiving, by definition, entails involvement in the well-being of another. Research or application of family systems in addressing caregiving of older family members is sparse and somewhat dated (Hughston, Christopherson, & Bonjean, 2012; Qualls & Williams, 2013; Smith, 2013). Further application of family systems to caregiving families is needed as having an elderly parent in ill health is associated with increased family conflict (Fuller-Thompson, 2000). As the theory asserts that individual emotional functioning influences how other family members function emotionally (Comella, 1995), it becomes clear that CGs must navigate their role in the context of current and past family dynamics. Initiation of a new phase of caregiving such as beginning coresidency with the CR and chronic stress of years-long caregiving are examples of the types of stressors that challenge an individual's differentiation. Smith (2013) suggested that in Bowenian theory, chronic stress is related more to internalization of fear than an actual threat or it may occur due to an "imagined threat to a desired relationship" (p. 211). "The long goodbye" (Dittbrenner, 1994, p. 14) of dementia caregiving is itself a continuous and very real threat to the relationship (Smith, 2013). Family conflict has been shown to increase the stress of caregiving (Sun, 2014) and poor family functioning is associated with higher CGB (Heru & Ryan, 2006). Caregiving has the

potential to rekindle latent, unresolved dysfunction in a family system, but this concept has not

been well-studied even though a systems perspective fits with the complex and interdependent

interactions of caregiving (BCFS, 2016h). Without considering the family system, researchers

and clinicians miss the perceptions of multiple family members and fail to grasp unique CG

family circumstances (Polk, 2005). A family systems view may be particularly salient in the

U.S. where older adult-offspring relationships are more highly characterized as disharmonious

than in five other developed nations (Silverstein, Gans, Lowenstein, Giarusso, & Bengston,

2010). A family systems lens was applied to the interpretative process of this research.

The Positive, the Negative, and the Ambivalent

Clearly, family relationships are complex, and that complexity is reflected in the CG-CR

relationship which develops within the family system. The quality of the CG-CR relationship is

associated with the obligation to care and the outcomes of caregiving (Wuest & Hodgins, 2011).

CGs can assume the role as an obligatory duty or an expression of filial devotion (Wuest &

Hodgins, 2011), though often there is ambivalence in the CG-CR relationship (Graham &

Bassett, 2006; Wilson, Shuey, & Elder, 2003). The preponderance of the literature addresses

burden and negative aspects of caregiving, but conflicted positive and negative feelings toward

the CR are common in offspring CGs (Wilson et al., 2003) and seemingly opposite emotions do

co-occur (Folkman, 2008). The caregiving experience can bring satisfaction or stress and often

brings both (Doka, 2003) with ambivalence fed by uncertainty about the future as the CR disease

process unfolds (Carpentier et al., 2008). Dementia caregiving has demonstrated simultaneous

outcomes of burden and positive gains (Lim et al., 2011). Research has also found that uplifts,

perceptions of positive aspects of caregiving, were negatively correlated with CG depression and

burden (Pinquart & Sorensen, 2003; Reinardy, Kane, Huck, Call, & Shen, 1999).

Research on the effects of stress may be ill served if the focus is only on the negative (Folkman, 2008). CGs, even in dire caregiving circumstances, have reported positive aspects 90% (Farran, 1997) and 99.5% (Folkman, 1997) of the time. More recently, CGs have reported caregiving rewards 65–76% of the time, again in intense and challenging situations (Wolff, Dy, Frick, & Kasper, 2007). There is limited evidence that CG experience of positive and negative affects may influence the capacity to function in the caregiving and other life roles (Moskowitz, Shmueli-Blumberg, Acree, & Folkman, 2012). Recognition of caregiving outcomes beyond burden can provide a balanced public perception of caregiving (Carpentier et al., 2008) and promote interventions that not only reduce burden, but also increase the experience of uplifts (Singer et al., 2009). The latter may be particularly salient for offspring CGs who experience more personal growth (Ott, Sanders, & Kelber, 2007) and greater rewards of caregiving than do spouse CGs (Raschick & Ingersoll-Dayton, 2004).

Positive psychology. Positive psychology, a "dual aspect theory" (Seligman, 2003, p. 127) of co-existing strengths and weaknesses in all people, recognizes the import of suffering and stress (Seligman, Steen, Park, & Peterson, 2005). Based on positive psychology, positive psychotherapy (PPT) emphasizes three aspects of happiness or well-being: positive emotions/pleasure, meaning, and engagement in life (Seligman et al., 2003; Seligman, Rashid, & Parks, 2006). Positive emotions may contribute to coping by increasing adaptability (Folkman, 2008), an important construct for successful caregiving (Coon, 2012) and for finding meaning in ambiguous losses such as dementia caregiving (Boss, 1999). Compared to positive emotions, meaning and engagement in life are more effective in combatting depression (Seligman et al., 2006) and potentially more amenable to change (Peterson, Park, & Seligman, 2005). Psychological well-being is strongly associated with meaning in life (García-Alandete, 2010;

Zika & Chamberlain, 1992) and one mechanism by which positive emotions increase coping is by finding meaning in stressful circumstances (Tugade & Fredrickson, 2004).

PPT is effective for depression (Guo et al., 2016; Lü, Wang, & Liu, 2013; Seligman et al., 2006), increasing self-efficacy (Guo et al., 2016), and potentially increasing biological stability under stress (Lü et al., 2013), important factors in CG well-being (van der Lee et al., 2014). There is a call for more strengths-based, positive interventions for CGs (Walker, Powers, & Bisconti, 2016). One component of PPT that is efficacious in reducing depression and increasing well-being at six-months follow-up entails putting one's strengths to work in new ways (Seligman et al., 2005), an activity that caregiving requires even if CGs do not recognize it. The emphasis of PPT on meaning may also be beneficial to CGs for whom finding meaning has been associated with decreased symptoms of depression (Fuhrmann, 2015).

Existential perspective. Stressful circumstances such as a loved one's diagnosis of dementia and the caregiving experience can be a source of existential loss and threat (Piiparinen & Whitlatch, 2011). Transitioning to caregiving—and this study suggests transitions within caregiving—can be times of uncertainty and ambiguity in which suffering itself leads to growth, self-transcendence, and new identities and meaning (Gibbons et al., 2014). Caregiving for CRs with dementia and Alzheimer's, "the long goodbye" (Dittbrenner, 1994, p. 14), particularly entails a complex, ambiguous, ongoing grieving (Juozapavicius & Weber, 2001; Loue, 2008), release of that which cannot be controlled, and reforging of self and the relationship (Todres & Galvin, 2006). Utilizing an existential lens to view the caregiving experience provides a means of understanding potentially positive outcomes in a phenomenon that entails suffering (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991). Finding meaning, especially spiritual meaning (Frankl, 2000), in suffering is foundational in existentialism as espoused by Frankl

(2006). Spiritual meaning is associated with lower levels of depression in dementia CGs (Lopez, Romero-Moreno, Marquez-González, & Losada, 2012) and mediates racial disparities in CGB (Sun, Kosberg, Leeper, Kaufman, & Burgio, 2010) and rewards (Picot, Debanne, Namazi, & Wykle, 1997). Frankl (2006) forged his own personal meaning in a concentration camp. Suffering as an idiosyncratic experience (Farran et al., 1991) cannot truly be compared, but dementia caregiving has been likened to life in a concentration camp (Levine et al., 1984), with its challenges to existential concerns of death, isolation, freedom, and meaning (Yalom, 2000).

Meaning-making, engagement in life, and personal identity. Finding meaning and being engaged in life are prime elements of happiness in positive psychology. For dementia CGs, personal identity is often challenged by the changing demands and relationships (Montgomery & Kosloski, 2009), and identity formation may be forged in the process of finding meaning in the caregiving role and learning how to engage in an altered way of doing life (Farran et al., 1991; Gibbons et al., 2014). Frankl (2006) stated that meaning can be found when life expects something of the individual and much is expected of the CG. When problem-focused and emotion-focused coping are not effective in dealing with a stressful situation, meaning-focused coping, which is the reappraisal of a situation that incorporates an individual's beliefs, values, and existential goals, may support more sustained coping, provide positive emotions, and restore resources needed to continue dealing with stressors (Folkman, 2008). Such a focus on meaning appears to be a core process in coping with stress (Folkman, 2008) and can be both protective and empowering (Wong, 2010). For the dementia CG, meaning-making mediates the relationship between the burden of caregiving and mental health (McLennon et al., 2011), suggesting that meaning-making is effective even when the CG continues to experience caregiving as difficult. Additionally, meaning-making mediates the association of CGB to

caregiving gains (Salmon, Kwak, Acquaviva, Brandt, & Egan, 2005).

The caregiving experience can conflict with the sense of self of the CG (Montgomery & Kosloski, 2009) and the onset of caregiving in conjunction with a CR diagnosis of AD can disrupt the very structure of life (Välimäki et al., 2012). However, transitioning into caregiving can be a time of positive, even transformative growth (Gibbons et al., 2014; Montgomery & Kosloski, 2009). An ongoing process of meaning-making and identity formation is often a part of dementia care as the disease progresses and the CG role continually changes (Golden, Whaley, & Stone, 2012). Some dementia CGs have become more spiritually enlightened through the caregiving experience (Välimäki et al., 2012). Caregiving inherently entails doing for another, and acts of generosity are associated with increased sense of competence, engagement, and life satisfaction (Chancellor, 2013).

Application of the positive and existential to the current study. This study meets the calls by researchers and even CG participants (Folkman, 1997) for greater balance of positive and negative factors in research on stressful situations (Farran et al., 1991; Folkman, 2008) and on caregiving (Walker et al., 2016) and more understanding of the processes of coping (Folkman & Moskowitz, 2000) and meaning-making in life circumstances (King, Hicks, Krull, & Del Gaiso, 2006) by listening for the positive, negative, and ambivalent reflections of the CGs and for ways in which they find meaning in their experience. Optimally, CGs seek out a middle ground on which they can retain personal autonomy and yet, often sacrificially, meet the needs of the CR (Hodgetts et al., 2003). Stressful life events have the potential to bring about positive changes in interpersonal relations, recognition of life opportunities, spiritual dimensions, gratitude, and personal strengths (Jayawickreme & Blackie, 2014; Tedeschi & Calhoun, 2004). These constructs closely align with the emphases of positive psychology on meaning-making,

life engagement, and positive emotions, and existential therapy on discovery of meaning in each

life situation (Batthyany, 2016) via deeds, suffering, and experiencing something or someone

(Frankl, 2006). This research was conducted with awareness of these constructs.

Specific Factors of Caregiver Well-Being

Beyond these constructs, there are specific influences on CG well-being. A multiple

regression analysis revealed seven factors that together predicted 81% of CGB, four of which,

CG gender, neuroticism, overload, and adverse life events, are unalterable or difficult to alter

(Campbell et al., 2008). The remaining three, discussed frequently in the literature, the quality of

the CG-CR relationship, role captivity, and confidence are amenable to intervention. Because of

the empirical support for the impact of these factors on CG outcomes and their relevance to the

conceptual framework for this study, they are discussed below.

The choice to care and role captivity. Role captivity is the perception of being trapped

in the caregiving role (Givens et al., 2014) when it is unwanted, involuntary, and perceived as

inescapable (Aneshensel, Pearlin, & Schuler, 1993). Half of all CGs endorse having little choice

in taking on the role, and that percentage increases for coresident CGs and those who spend more

hours caregiving (AARP-PPI & NAC, 2015a). Dementia CGs have been shown to have a

greater level of role captivity compared to other CGs (Bertrand et al., 2006; Givens et al., 2014),

experience the stress of role captivity differently (Bertrand et al., 2006), and strive to maintain

their own agency while witnessing the CR inevitably lose control (Golden et al., 2012). The

medical system typically assumes CGs will take on the role when CRs are diagnosed with AD

(Välimäki et al., 2012). Role captivity is particularly important related to dementia caregiving as

it, along with CR problem behavior, fully mediated the higher level of depression in dementia

CGs (Givens et al., 2014). Because the quality of the precaregiving CG-CR relationship is

associated with decrease in perceived role captivity (Quinn, Clare, McGuinness, & Woods, 2012), family systems theory may provide insight into interventions to potentially alter role captivity. Social systems and culture are also salient as European American CGs differ from other American racial and ethnic CGs in their lack of caregiving as an embedded value (Pharr et al., 2014) and their higher level of intrapsychic strain from caregiving (Hilgeman et al., 2009). Since European American CGs have demonstrated higher levels of role captivity (Morano & Sanders, 2005), it is possible that role captivity is relevant to their being less likely to see caregiving as a normative role and their higher levels of strain and burden (Hilgeman et al., 2009). Increasing understanding of the lived experience of dementia CGs can shed light on the important phenomenon of role captivity.

Self-efficacy. Role captivity occurs in the uncertainty of dementia caregiving, including CR behaviors, embedded in the certainty of disease progression. Having a measure of certainty regarding one's capacity to function in the CG role, appears to be a protective factor for CGs (Gallagher et al., 2011). Self-efficacy, the belief that one can be competent in a given role, mediates the effect of caregiving on CG well-being (Hajek & König, 2016). Self-efficacy related to caregiving appears to be strongly associated with positive outcomes for CGs (Cheng, Lam, Kwok, Ng, & Fung, 2013; Lopez et al., 2012; van der Lee et al., 2014) and a qualitative study suggested one reason may be that it induces greater hope that the CG will be able to sustain the role as the CR requires increasing levels of care (Välimäki et al., 2012).

The dyadic relationship. The noted potential incongruity between caregiving and personal identity may also extend to the relationship as CGs struggle to forge new role identity with the CR (Montgomery & Kosloski, 2009). Successfully navigating the role transition, an ongoing process, resulted in satisfaction with personal identity and in increased caregiving self-

efficacy (Simpson, 2010). While the CG-CR dyad exists within a family system, it is important

to be aware of the quality of the dyadic relationship which is associated with CG depression and

anxiety (Mahoney et al., 2005). CR dementia negatively affects the dyadic relationship

(Gallagher-Thompson, Dal Canto, Jacobs, & Thompson, 2001). Strain in that relationship is

associated with negative CG outcomes, including depression (Lyons, Zarit, Sayer, & Whitlatch,

2002), but, despite the dementia care stresses and the cognitive limitations of the CR, the dyadic

relationship can be a source of reward and enrichment for the CG (Graham & Bassett, 2006).

Summary of Conceptual Framework

The dementia caregiving dyad exists within and mutually influences the family,

caregiving, and societal systems. It is a relationship with ongoing transition as the disease

process occurs, suggesting change and challenge to the relationship and the CG's personal and

role identities. The potential growth and navigation of the challenges occur as CGs experience

positive, negative, and ambivalent aspects of the experience and the relationship. The striving

for meaning and engagement in life can happen in any of the noted systems or, transcendently,

beyond those systems. Offspring CGs likely forge their identity and meaning while engaged in

multiple relationships and triads within their own immediate family system and in work or other

nonfamilial responsibilities. These may be sources of additional burden or meaning, but clearly

reflect complexity in the offspring CG milieu. This study addresses the positive, negative and

ambivalent experiences of the participant dementia CGs through a systemic lens, attending to the

CGs' identities, meaning-making, and idiosyncratic complexities.

<div align="center">

Research Approach

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This study utilizes interpretative phenomenological analysis (IPA), which focuses on

significant life experiences (Smith et al., 2009) that are important to individuals (Smith &

Shinebourne, 2012), the meaning of those experiences to the individuals, and how they make sense of the experiences. IPA provides a methodology to connect personal lived experiences to each other, the researcher, and ultimately the readers (Varela, 1996).

Philosophical Underpinnings

IPA has a three-pronged philosophical base: phenomenology, hermeneutics, and idiography (Smith et al., 2009).

Phenomenology. IPA draws on the work of phenomenological philosophers, including Heidegger, Husserl, Sartre, and Merleau-Ponty, to form a holistic perception of phenomenology (Smith & Shinebourne, 2012). Phenomenology privileges subjective experience, not as the only way of knowing, but as necessary for knowing (Moran, 2000). It entails "a process of revealment" (Heidegger, 2003, p. X) via description of a human phenomenon in order to encounter something previously unobserved and uncover the truth within it (Moran, 2000). The phenomena of interest are conscious, lived experiences and the early phenomenologists sought, in contrast to rationalism and reductionist empiricism, to conduct inquiry via "living contact with reality" (Moran, 2000, p. 5). Sartre (1943/1984) believed such reality occurs interpersonally and that human life is continually developing. More recently there was a call for phenomenological perspectives to incorporate subjective experience in the study of neuroscience (Varela, 1996). From its inception, phenomenology was identified as descriptive psychology and it privileges description over causation or explanation (Moran, 2000). Husserl (1913/2012) and Merleau-Ponty (1945/2012) believed phenomenology is needed to support and clarify science. As posited in IPA, phenomenology respects other forms of inquiry, but finds benefit in the resultant rich descriptions on their own and as complements to quantitative results obtained by traditional scientific methods (Smith et al., 2009; Varela, 1996). IPA brings to life the phenomenon of

interest by its rich descriptions and interpretation of those descriptions.

Hermeneutics. While Husserl (1913/2012) advocated conducting phenomenological inquiry without presupposition to avoid distorting the phenomenon of interest, Heidegger's assertion that description is of necessity an interpretative activity (Moran, 2000) is adopted in IPA's hermeneutic stance (Smith et al., 2009). In IPA, the researcher has a dual role of engaging with participants and interpreting (Smith & Shinebourne, 2012). The phenomena of interest are self-manifesting in phenomenology (Heidegger, 2003) and must be understood from the participants' perspectives (Smith et al., 2009), requiring the interpreter's preconceptions be clarified, and their inevitable influence acknowledged and bracketed, albeit imperfectly (Smith et al., 2009). Once the primary sense of the participants' contextually situated perspectives is analyzed, deeper meanings and interpretations are beneficial but must be consistent with the primary meanings (Elwell, 2001). In IPA, the deeper meanings arise from analysis of the data, from the researcher's knowledge, and from relevant theoretical constructs (Smith et al., 2009).

Idiography. In keeping with the noted privileging of the subjective in phenomenology, IPA emphasizes idiographic experiences. The emphasis is on the details of particular cases and contexts, deeply analyzed, in contrast to traditional scientific inquiry which seeks primarily generalizations (Smith et al., 2009). IPA utilizes a small number of participants to support thoroughness in the analysis of individual cases and to assure identified convergence, divergence, and potential generalizations are always connected back to the particular (Smith & Shinebourne, 2012). Analysis across cases does not occur until each individual case has been thoroughly analyzed (Smith, 2004). The aforementioned concept of bringing to life is reflected in the IPA claim that in deeply understanding a particular personally situated phenomenon, a connection is made to universal human experience (Smith, 2004).

Methodology and Use of IPA in the Current Study

IPA utilizes interviews and other idiographic data sources and extensive interpretative analysis that recognizes the person of the researcher as an interpreter who connects emergent themes to the existing literature (Smith, 2011b). IPA brings to light motivations and experiences, with the aim of "captur[ing] experiential convergence and divergence" (Smith, 2011b, p. 60). This study seeks to achieve IPA's aim by exploring the experiences, motivations, and meaning-making of the CGs, while connecting the themes that emerge to the literature.

The emphasis on meaning-making and the capacity of IPA to address issues of personal identity during life transitions (Smith et al., 2009) make it well suited to this inquiry. Caregiving entails transition to a new role, and in dementia caregiving there is an element of continual transition (Montgomery & Kosloski, 2009). Offspring CGs are in the unique position of making that transition in relationship to an individual who influenced their identity formation. Conflict between CG identity and the caregiving role appears to contribute to CGB (Montgomery & Kosloski, 2009), supporting the import of better understanding this phenomenon.

In IPA, studying phenomena of existential significance is recommended (Smith, 2011b) with intent to gather rich data from homogenous participants (Smith et al., 2009). This research, then, entailed interviewing female offspring CGs who were living with their CR parent, based on the higher risk of emotional strain amongst female CGs and those living with the CR (Caputo, Pavalko, & Hardy, 2016; Mahoney et al., 2005). In-depth interviews of six coresident offspring CGs were conducted. The interview data were supplemented by participant journals based on the interview questions and analyzed according to IPA recommendations. The resultant rich descriptions of CG experiences and emergent themes with awareness of convergence and divergence of participant data (Smith, 2011b) is reported and related to the literature.

Definition of Key Terms

Prior to embarking on this research, it was important to define and clarify key terms that are related to the topic of the study and that are found in the literature. These are not dictionary definitions but are more specific to the current work. For instance, *caregiver* has a broad meaning, but when used alone here, it refers only to informal caregivers. The definitions allow the reader a greater understanding of the researcher's denotation of the terms *dementia*, *caregiver*, *caregiver stress* or *burden*, and *offspring*.

Dementia

Dementia was defined in the fourth edition of the *Diagnostic and Statistical Manual* as conditions that entail changes in multiple cognitive domains with variant causation (American Psychiatric Association [APA], 2000). In the fifth edition, dementia is incorporated into the major neurocognitive disorders, acquired conditions in which the primary symptoms are cognitive (APA, 2013). The word *dementia* remains in use (APA, 2013), is common in the literature, and provides a broad term to incorporate multiple etiologies, of which AD is the most common (AA, 2016b). Because of its predominance as a cause of dementia, the term *Alzheimer's disease and related dementias* is also found in the literature.

Gradual onset, a primary presentation of memory loss, and no other clear etiology are indicative of AD, but without clear pathophysiological evidence, the diagnosis is possible or probable AD (APA, 2013; McKhann et al., 2011). Though the capacity to accurately diagnose AD and other dementias has greatly improved (AA, 2016b), dementia remains an accurate description of the clinical presentation, while AD refers to the neurobiological changes (McKhann et al., 2011). AD dementia is the diagnosis when, by history and neuropsychiatric testing, it is determined that individuals have significant functional impairment that differs from

their cognitive or behavioral norms in capacity to learn and retain information, executive

function, visuospatial skills, personality, and behavior (McKhann et al., 2011). In addition to

AD and mixed dementias, other common causes, excluding motor system disorders, are vascular

dementia, frontotemporal lobar degeneration, and dementia with Lewy bodies (APA, 2013). The

tragedy for those with these diagnoses and their CGs is that the conditions are progressive,

irreversible, and incurable (AA, 2016b).

Caregiver

The term *caregiver* is inclusive of professionals and laypersons who provide personal

services to an individual whose physical or mental limitations require the assistance of others.

This study focuses only on lay CGs, also referred to as informal or family CGs. A few programs

allow for a family CG to receive payment and families may pay the primary CG, blurring the

lines of formal/professional versus informal/lay CGs. For this study, in keeping with the

majority of the literature, CG participants are unpaid. For simplicity, *caregiver* here refers to

informal CGs. When discussing formal/professional CGs such as nursing assistants, home health

aides, and nurses, they are referred to by their title or as *formal CGs*. Informal caregiving

typically occurs between persons with an existing personal relationship although that may not

entail kinship (Kasuya, Polgar-Bailey, & Takeuchi, 2000). Tasks of a CG can vary greatly and

generally fall under the categories of activities of daily living (ADLs), instrumental activities of

daily living (IADLs), and psychosocial support. ADLs are tasks related to personal care, such as

bathing, dressing, and feeding. IADLs are less personal activities needed to sustain oneself such

as shopping, cooking, laundry, and medical and financial management. Psychosocial supports

may entail validation of the worth of the CR and reassurance by telephone or visitation.

Dementia CGs also engage in supervision to prevent wandering off or unsafe behaviors.

Caregiver Stress or Burden

In the most common measure of CGB, the construct is defined as the perception of caregiving-induced physical, psychological, emotional, social, and financial difficulties (Schreiner, Morimoto, Arai, & Zarit, 2006) with each item asking the CG a question beginning with "Do you feel" (Bédard et al., 2001, p. 657). Thus, what is measured is subjective burden which is not consistently associated with the amount of objective burden, the amount of time, number of tasks and difficulties of the tasks of caregiving (Sanborn & Bould, 1991). CGB is increasingly considered a multidimensional construct (van der Lee et al., 2014), incorporating burden on the CG-CR relationship, the noted objective aspects, and the subjective psycho-emotional stress of caregiving (Savundranayagam et al., 2011). CGB is also etiologically multidimensional, with physical, psychological, emotional, social, financial (Kasuya et al., 2000), familial (Adams, Mosher, Cannady, Lucette, & Kim, 2014), and spiritual factors (Doka, 2003). A mixed methods study concluded that CGB is complex and idiosyncratic (Galvin et al., 2016), agreeing with the concept that CGB occurs when the demands of caregiving are incongruous with the identity of a CG (Montgomery & Kosloski, 2009). For this research, CGB is a CG's perception of negative consequences attributed to the caregiving experience in any number of dimensions. When referencing the objective aspects of CGB specifically, *objective burden* is explicitly stated.

Offspring

While some of the literature uses the term *adult child* to refer to the offspring of a parent with dementia (Gaugler, Reese, & Mittelman, 2016), the current study avoids the confusion of using the word *child* when referring to adults. While *offspring* can infer biological parentage, that is not the intent here. Rather, its usage is meant to encompass any individual born to,

adopted by, or otherwise brought under the care and nurturance of the parent with dementia and whom that parent has considered his or her child throughout their relationship. No attempt was made to distinguish stepchildren, unofficially adopted children, or other unique circumstances, but instead the focus is on the perception of a parent-child relationship.

<div align="center">**Limitations and Significance of the Study**</div>

Both quantitative and qualitative research are inherently limited in scope and both methodologies are valuable for more complete understanding (McLeod, 2011). This research has limitations, delineated below. Its intent is to add to the knowledge base to improve mental health services for CGs and to support social change to improve the lives of CGs and CRs.

Limitations and Bounds of the Study

As with most qualitative research, the results of the current study have limited generalizability. That is not a weakness per se, however, as the standards for valid qualitative inquiry differ from those of quantitative endeavors (McLeod, 2011). The problem of dementia care in a rapidly aging population is vast and this study provides only a small piece of additional information to address the problem, limiting its consequential validity. No method of research can investigate a phenomenon for all populations. The participants for this research were chosen to meet the purposes of the study, but as discussed below, greater understanding of mental health needs and resiliency factors for other groups of participants are needed.

Diversity. As the population ages, the makeup of older Americans is becoming more diverse (Schulz & Eden, 2016). Dementia occurs across all populations and research on dementia caregiving addresses racial and ethnic differences and crosses international boundaries. Intervention research, however, is only now considering application of evidence-based treatment to a specific ethnic group of CGs (Luchsinger et al., 2016). A consistent finding in the literature

is that in the U.S., European American CGs, often despite having access to greater resources, experience more burden and negative outcomes from caregiving than other CGs, particularly African American CGs (Chiao, Wu, & Hsiao, 2015; Kosloski et al., 1999; Mbiza, 2015; Pinquart & Sorensen, 2005; White, Townsend, & Parris Stephens, 2000). Research shows more negative outcomes (Perrig-Chiello & Hutchison, 2010) and higher levels of caregiving for female CGs and most offspring CGs are daughters (Wolff et al., 2016). This study initially intended to look specifically at European American female CGs to address CG mental health needs by focusing on those with the highest reported burden. The choice of participants does not negate the importance of the mental health needs of all CGs, culturally specific aspects of CGB, or the reasons behind the few studies that demonstrate similar burden across racial and ethnic groups. Clarifying the sometimes-muddy picture (Jones, Lee, & Zhang, 2011) and looking at resilience factors that African American CGs exhibit consistently in the literature, the role of spirituality and religiosity which have been noted to mediate the racial differences (Picot et al., 1997; Sun et al., 2010), and less studied populations such as Native Americans and male CGs are important avenues for further research.

Significance of the Study

Despite the limitations noted above, the current study gave voice to a group of dementia CGs, potentially offering valuable insight to counselors and other mental health providers. Giving voice to the participants is itself an act of social justice (Foster, 1994), empowering both CGs and the CRs for whom they advocate. The significance of enhanced mental health interventions for dementia CGs offers benefits for CGs, CRs, and society.

Professional application. Those who provide care for PWDs are at risk for stresses that challenge their mental health (Riedel et al., 2016; van der Lee et al., 2014; Wolff et al., 2016).

There is minimal research to guide choice of intervention for mental health professionals working with dementia CGs, less that provides the clinician with an understanding of how these clients experience the rewards and challenges of their role, and very little that addresses those concerns specifically for offspring CGs. For instance, out of 79 references in this work that specifically address dementia CG mental health, 28 give guidance to mental health providers via a systematic review (Petriwskyj et al., 2016) and a meta-analysis (Spijkew et al., 2008), information for CG assessment (Branger, O'Connell, & Morgan, 2016; Farran, Miller, Kaufman, Donner, & Fogg, 1999a, 1999b; Fortinsky, Kercher, & Burant, 2002; Kiriake & Moriyama, 2016; Rankin, Haut, & Keefover, 1992), and six specific interventions. Four of those interventions are little studied (Andrén & Elmståhl, 2008a; Chiu et al., 2015; Mahoney et al., 2005; Mitrani & Czaja, 2000). The remaining two interventions have been studied extensively, with guidance provided for implementation (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003; Cheung et al., 2015; Elliott, Burgio, & DeCoster, 2010; Fauth et al., 2019; Gaugler et al., 2013, 2015, 2016; Luchsinger, et al., 2016; Mittelman, 2002; Mittelman et al., 2003, 2004; Mittelman, Brodaty, Wallen, & Burns, 2008; Mittelman, Roth, Clay, & Haley, 2007; Schulz et al., 2003; University of Michigan's Institute of Gerontology & The National Association of Chronic Disease Directors, 2009; Wisniewski et al., 2003). Only a recent extension of one intervention has been provided specifically for offspring CGs (Gaugler et al., 2013, 2015, 2016). The current research intends to add to the knowledge base the voices of offspring dementia CGs as they speak to the lived experience of coresident caregiving to more clearly guide interventions to address their mental health.

Positive social change. This study, like the preponderance of the literature on the CG-CR dyad, focuses on the CG. It can be easy to forget that there is a recipient of care who contributes

to the relationship (Graham & Bassett, 2006). As noted above, more lived experiences related to

dementia need to be researched and the experiences of PWDs are understudied and their voices

need to be heard (Munro, 2015). Those who advocate for person-centered care, suggest support

for the CG is a form of supporting the CR (Picker Institute Europe, 2016). Giving voice to CGs

who are often advocates for CRs promotes awareness of CR needs. By increasing insight into

the mental health needs of CGs to inform effective interventions, the lives of both members of

the dyad can be improved. Effective interventions have been shown to delay nursing home

placement (Gaugler et al., 2013; Mittelman, 2002), an outcome desired by most CRs (Mathew

Greenwald & Associates, Inc., 2003).

Effective interventions that enable CGs to remain and find positive meaning in their roles

contribute to the needs of a society anticipating increased public burden of dementia care. More

existentially, when the dignity and worth of CR and CG are enhanced the world is a better place

if it is true that when one "ceases to care he ceases to be human" (Heschel, 1997, p. 229). The

plight of dementia is worldwide yet profoundly intimate. We are all affected indirectly, and no

one knows when and if we will deal with it in those we love, or they will deal with it in us.

Chapter Summary

In support of the worth and dignity of PWDs and their CGs, this study sought to give

voice to each offspring dementia CG and shed light on her lived experience, the meaning she

finds, and the identity she forges as she strives to make sense of the CG role, and on the mental

health needs she articulated. From the data, the researcher sought to present deep layers of

connected meaning: connecting the participants' stories to each other; the data to the conceptual

framework; the researcher's perspective tentatively to that of the participants; and readers, future

researchers, policy makers, and clinicians to the participants.

Chapter Two reviews the literature to support the need for the study and aptness of the methodology. Chapter Three details the methodology. Chapter Four provides research findings and connects them to the conceptual framework and research questions. Chapter Five discusses the findings' implications, relevance to counseling, and research recommendations.

CHAPTER TWO: LITERATURE REVIEW

In IPA, the literature review serves to identify gaps in the knowledge base where deeper understanding of complex phenomena is needed (Smith et al., 2009). The goal is not to derive research questions from theory, but the literature can inform researchers about the proposed participants in a general way (Smith et al., 2009) and assure the relevance of interview questions.

This literature review follows the conceptual framework and research questions, with the following sections: family, caregiving, and societal systems, the dyadic relationship, caregiver identity, making sense and finding meaning, and, based on the primary research question, the mental health needs of offspring dementia caregivers, with a subsection that looks at mental health treatments. For each section, consideration is given to the contribution of qualitative research. The literature review ends with a discussion of the qualitative method being used in the current study, IPA, and its application to the topic of dementia caregiving.

A literature search was conducted from January 2017 through April 2018. Studies printed in English between 1980 and 2017, inclusive, were included if derived from peer-reviewed journals, conference proceedings, dissertations and theses from accredited colleges and universities, reports from government and United Nations agencies and from the World Health Organization, and reports from nonprofit agencies such as AA and AARP. The agency resources were only used when it was clear the contributors were subject experts working collaboratively. Because of the nature of this study, qualitative, quantitative, and mixed methods research were included.

The following terms were used through the search engine, EBSCO Quick Search: *caregiver, carer,* a term used in the international literature, "mental health," *stress, burden, dementia, Alzheimer's, NCD,* "neurocognitive disorder," *offspring, child, son, daughter,* "family

system," "caregiving system," "societal system," dyadic relationship, meaning, "meaning-making," *existential, identity, interpretative phenomenological analysis, IPA, counseling, female,* and *wife.* Appendix A shows the search terms as they were entered in the search engine.

Further studies were found in reference pages of the literature or from data compilations such as the Alzheimer's Disease Facts and Figures (AA, 2018b) when a study needed further clarification, a topic merited expansion, or there was a connection to the current study. Those studies were accessed via the Liberty University online library, Google Scholar, or, rarely, via direct access through the National Institutes of Health or ResearchGate. When the literature was sparse on a dementia caregiving topic, salient research on general caregiving was included.

There was limited empirical research on the societal system, yet it was important to place the phenomenon into the societal milieu. Following references from a Welsh study (Cascioli, Al-Madfai, Oborne, & Phelps, 2008), it was possible to paint a picture of Welsh public policy development. To discover whether the US, where this study was conducted, has developed similar policy, AA announcements regarding legislation and actual legislation were used.

Research focused primarily on caregivers of children or adults under the age of 50 or on individuals whose primary need for care is due to nondementia psychiatric conditions were excluded. This review did not include studies that focused on paid caregivers. Research on nonclinical interventions for CGs is vast, including training in caregiving, services for the CR such as adult daycare, and case management, but for the purposes of this study, the discussion was limited to studies that had a clear mental health component of treatment with relevance to offspring dementia CGs. Studies were excluded if the primary outcomes or focus were on CRs.

Systems

Caregiving is a phenomenon whose complexity has often been oversimplified in research

that has given only limited attention to the systems in which it occurs (Nolan, Ryan, Enderby, & Reid, 2002). There has been recent work in Japan to consider the value of CGs partnering with the family, societal, and caregiving systems (Kiriake & Moriyama, 2016). That work, embedded in the milieu of contemporary Japanese culture, consisted of preliminary development of an assessment instrument measuring the capacity of family dementia CGs to form partnerships with other family members and with caregiving professionals (Kiriake & Moriyama, 2016).

The Family System

Twenty-eight years ago, Rankin et al. (1992) suggested that interventions for dementia caregivers would be more effective from a family systems rather than a dyadic perspective, noting that variables in the family system can be sources of support or stress. By assessing 121 memory clinic patients and conducting systemic interviews and a battery of assessments with the caregiving families, the authors clarified family system contributors to CG depression and CGB (Rankin et al., 1992). In hierarchical regression analyses the greatest variance in CGB was correlated with CR behavior and memory problems ($R^2 = .37$) followed by nearly equal variance related to caregiving activities ($R^2 = .07$) and family support ($R^2 = .06$); and for caregiver depression, perception of mastery contributed the greatest variance ($R^2 = .20$), followed by CG physical health ($R^2 = .14$), with contextual variables and intrafamilial stressors contributing equally ($R^2 = .08$; Rankin et al., 1992). Of interest is that family support contributed greater variance to CGB than did CG sense of mastery and intrafamilial stressors contributed greater variance to CG depression than did contextual factors, history of recent loss, and the ability to acquire social supports (Rankin et al., 1992). This suggests addressing intrafamilial stress and promoting family support may lessen CGs' experience of burden and depression. Seeking to promote systemic assessment of caregiving, the researchers also identified family support and

stressors as important factors in CG outcomes (Rankin et al., 1992).

A decade earlier, it was suggested those working with dementia CGs should consider the history, expectations, and systemic organization of the family (Gwyther & Matteson, 1983). Gwyther and Matteson (1983) also noted that attention to adult siblings in the caregiving family system was lacking. There is no evidence in the literature that an observational study begun at that time designed to deepen understanding of the quality of the family system as a context for dementia caregiving was completed (Niederhehe & Fruge, 1984). The need for aging research from a family systems perspective was again called for by Blieszner and Bedford (2012). These calls have not been well heeded, as there is little caregiving research that considers the family system, particularly for dementia caregivers. Much of that research was contemporaneous with or preceded the call by Rankin et al. (1992). Exceptions are a recent study of primary and secondary family CGs, looking at a triad with the CR (Alva, 2016), and research around a successful intervention, the New York University Caregiver Intervention (NYUCI), for spousal CGs that incorporates the family in treatment (Mittelman et al., 2008).

The first exception considered quantitative and qualitative data regarding collective caregiving by primary and secondary CGs and the interdependence of those CGs (Alva, 2016). The primary CGs took a lead role and spent the most hours caregiving. Secondary CGs had auxiliary roles and provided fewer hours of care. That understanding of primary and secondary CGs holds throughout the current study. Twenty-six caregiving dyads completed online questionnaires to identify differences between primary and secondary CGs and associations between one CG's appraisals and the other's outcomes (Alva, 2016). Significant results in which the members of the dyad differed were that only primary CGs had significant levels of depressive symptoms, bother due to CR behavior was associated only with level of depression in

the primary CGs and only with CG burden in the secondary CGs, and the only correlation with

CR care bother was with secondary CG burden (Alva, 2016). Interdependence was

demonstrated in only one direction with no correlation of primary CG appraisals of the

caregiving situation on the secondary CG, but a positive correlation of secondary CG appraisal

of CR behavioral problems to primary CG depressive symptoms (Alva, 2016). The reason for

this correlation is unclear, but the researcher suggested possible connection to the qualitative

results that demonstrated notable concern by the secondary CGs for the well-being of the

primary CG and by the primary CG related to negative family relationship factors (Alva, 2016).

The analyses did not control for CG gender, which may have been useful as 88.5% of the

primary CGs were female versus 61.5% of the secondary CGs (Alva, 2016). The results were

unexpected regarding the degree of similarity between primary and secondary CGs subjective

appraisals of the caregiving experience. The study did not address the potential confound of

caregiving dyads in which both were willing to participate in the study, i.e. less harmonious pairs

may have less similar appraisals. This supports the author's assertion that deeper understanding

of caregiving necessitates consideration of the family system (Alva, 2016).

When the NYUCI was extended to offspring CGs, CG reactions to CR behavior were

reduced, but the offspring CGs largely rejected the family system portion of the intervention

(Gaugler et al., 2016). The NYUCI is designed to be individually tailored, but it is striking that

in its original form the ratio of individual to family counseling sessions was 2:4, but the offspring

adaption ratio was close to 4:1, with nearly half the participants choosing no family session

(Gaugler et al., 2016). The reasons for offspring CG resistance to family counseling are not well

understood and were not addressed when the intervention's external validity was studied across

multiple sites (Fauth et al., 2019). That study included both spouse and offspring CGs, but the

participants were nearly 90% spouses (Fauth et al., 2019). The authors did not address whether

attrition, most frequently associated with CG or family members not wanting to continue

participation, was associated with whether the CG was a spouse or offspring of the CG or

whether, as in the Minnesota adaptation, offspring were less interested in the family counseling

module (Fauth et al., 2019). Because the multisite study found the NYUCI was associated with

significant changes in external factors such as social support and family conflict, but not internal

factors such as depressive symptoms, the authors suggested future research consider whether the

family counseling component contributes to external outcomes and the individual counseling to

internal outcomes (Fauth et al., 2019). A dismantling study may be worthwhile, but there is

evidence from meta-analyses that multicomponent interventions for CGs are most beneficial

(Sorensen, Pinquart, & Duberstein, 2002; Spijkew et al., 2008). However, randomized control

trials (RCTs) of the NYUCI demonstrated differences in acceptability of its family counseling

module by relationship to the CR; the investigation of external validity of the NYUCI found

greater effects on family conflict, but less on internal indicators of distress; and, other than in its

Minnesota adaptation (Gaugler et al., 2015), the vast majority of CGs who have benefited from

the intervention have been spouses of the CR (Fauth et al., 2019; Mittelman et al., 2007, 2008).

Thus, prior to a dismantling study, better understanding CGs, particularly offspring CGs, from a

family systems perspective may be needed.

   Bidirectional influence of preexisting and caregiving factors.

   Preexisting factors. A family's history of conflict and capacity to function as a team

influence its experience of caregiving for an aging parent (Merrill, 1996). Previous patterns of

dysfunction, for example related to a parent with an alcohol use disorder, influence how the

family system responds to caregiving needs (Merrill, 1996). It has been suggested that the

stresses of caregiving and prolonged grief such as experienced in dementia, may rekindle preexisting family problems (Berezin, 1970).

A family's established patterns related to decision-making, dealing with emotional issues, and solving problems were associated with the amount of caregiving provided and decisions to institutionalize the parent with dementia, though it is not entirely clear if these patterns were established prior to caregiving (Lieberman & Fisher, 1999). These researchers studied 211 dementia caregiving families by considering the data provided by one offspring CG for each family completing a questionnaire and interview. Family decision-making and conflict resolution, based on the interview data, were rated on positive decision making/focused decision making and positive conflict resolution/task focus, respectively (Lieberman & Fisher, 1999). Focused decision-making was a composite of how many people were involved in the decision and how much discussion it entailed (Lieberman & Fisher, 1999). The authors suggested that the results reflected the division of families into collectivist and individualistic values described by Pyke and Bengston (1996). This suggestion is in keeping with more recent research that demonstrated notable cultural differences, a clearly preexisting family dimension, in dealing with caregiving (Coon et al., 2004; Dilworth-Anderson et al., 2005).

However, in examining the relationship of family functioning to dementia CG outcomes for non-Hispanic European Americans and Cuban Americans, ethnicity did not moderate the results (Mitrani et al., 2006). For this study, family function, defined as cohesion/enmeshment, disengagement of the family from the CR, positioning of the CR as a patient by the family, conflict resolution, and expression of positive affect and of anger, was measured by the observer-rater based Structural Family Systems Ratings–Dementia Caregiver Subscales (Mitrani et al., 2006). For the 181 families in this analysis, family function was shown to mediate the effect of

objective burden on CG distress, operationalized as depression, anxiety, and perceived health. When demographic variables were controlled for, family function contributed 6.7% of the variance in CG distress (Mitrani et al., 2006). In applying the results of this study, two of the authors found that assessment of family function is a valuable guide in providing therapy to dementia caregiving families (Mitrani & Czaja, 2000).

The impact of caregiving on the system. Caregiving stresses can impact family members of the primary CG (Pruchno, Peters, & Burant, 1995). In a mixed methods study, most reports of family conflict were related to primary CGs' perceptions of needing more help from other family members (Merrill, 1996). Even cohesive families that respect each other's opinions can find the decisions related to dementia caregiving conflictual (Brodarick, 2014).

Family conflict. CGs have cited family conflict as a significant source of stress in caregiving (Rabins, Mace, & Lucas, 1982). An early study that found a connection of interpersonal conflict to CG strain and negative emotion such as anxiety and depression, considered only the conflict between the CG and the CR and not within the larger family system (Sheehan & Nuttall, 1988). Conflict within the family system, considered narrowly as family conflict resulting from the caregiving situation, fully (Kwak, Ingersoll-Dayton, & Kim, 2012) and partially (Scharlach, Li, & Dalvi, 2006) mediated the impact of CR cognitive and general impairment on CG strain (Kwak et al., 2012; Scharlach et al., 2006). An additional concept of importance is the suggestion that what is stressful is not the presence of conflict in the caregiving family, but the manner in which the family deals with conflict (Lieberman & Fisher, 1999).

Intergenerational conflict. The above noted study that found a correlation of CG-CR interpersonal conflict to CG strain and negative emotion, gave insight into intergenerational conflict, as 77% of the participants were offspring (Sheehan & Nuttall, 1988). Thus, there was

conflict between offspring CGs and parent CRs (Sheehan & Nuttall, 1988). Conflict was also

intergenerational when the CRs were spouses of the CGs. Those spouse CGs most frequently

reported family conflict occurred with their offspring (Semple, 1991).

Sibling conflict. Within the family system, CGs' siblings can be a source of conflict

(Kwak et al., 2012), potentially explaining the resistance to family counseling by CGs in the

Minnesota adaption of the NYUCI. There is evidence that family conflict in dementia care

occurs most often between siblings (Peisah et al., 2006; Strawbridge & Wallhagen, 1991).

Reasons for the conflict may be lack of assistance in caregiving from their siblings (Merrill,

1996; Strawbridge & Wallhagen, 1991), accusations against the caregiver related to care

(Rabins, Mace, & Lucas, 1982), or extensions of preexisting conflicts (Peisah et al., 2006). Lack

of caregiving assistance appears to be a source of frustration for CGs because it is often counter

to personal (Suitor & Pillemer, 1996) and societal expectations (Semple, 1991) that adult

offspring will provide care. Research on sibling conflict in dementia care often neglects "more

diffuse and longstanding" (Semple, 1992, p. 654) preexisting conflict. While Pearlin and

Aneshensel (1994) proposed that family conflict in caregiving is a secondary stressor proliferated

by the primary stressor of caregiving, Pearlin and Bierman (2013) later acknowledged that the

influence of chronic stressors such as caregiving is often influenced by preexisting stressors,

such as family conflict. This suggests that the difficulties that arise in a caregiving family are

likely influenced by caregiving itself and by preexisting family patterns.

Family cooperation. Family conflict is clearly a potential source of distress to CGs.

However, CGs may also have positive experiences of the family in caregiving. For example, in a

study of autonomy in family caregiving systems, half of families reported joint coordination of

caregiving and 57% reported working well together (Cicirelli, 1992).

Intergenerational cooperation. As would be expected from a systemic perspective, respect of adult offspring for their older parents' autonomy is associated with greater sibling cooperation among the offspring in carrying out parent care (Cicirelli, 1992; Ingersoll-Dayton, Neal, Ha, & Hammer, 2003a). Offspring with whom elderly parents were consistent in how they communicated their wishes were able to cooperate in parent care (Ingersoll-Dayton et al., 2003a). Sheehan and Nuttall (1988) found a negative correlation of CG affection for the CR to CG strain and negative emotion, although it was less robust than the correlation to conflict.

Sibling cooperation. While two thirds of siblings caring for a parent were inequitably sharing the responsibilities, it is notable that one third were able to establish equitable caregiving arrangements (Ingersoll-Dayton, Neal, Ha, & Hammer, 2003b). When siblings see each other's perspective and value mutual solutions in the caregiving dilemma, even with conflict, there appears to be greater satisfaction with caregiving (Weitzman, Chee, & Levkoff, 1999). Ninety-four percent of offspring CGs in a focus group spontaneously raised the subject of sharing caregiving with siblings, even though they were not asked about it, evidence that equitable caregiving was important to them (Ingersoll-Dayton et al., 2003a). Simple requests and communication can turn inequitable sibling caregiving into teamwork (Ingersoll-Dayton et al., 2003b). Caregiving among siblings who perceived it as more equitable expressed awareness of the family as a collaborative system, although the capacity to do so may stem from already positive sibling relationships (Ingersoll-Dayton et al., 2003a). An in-depth qualitative study of 149 sibling pairs of older parents, that did not focus on stress and burden, explored how families decide the division of care of a parent and found siblings described a more positive experience than much of the literature (Matthews, 2002). The more optimistic finding of these siblings suggests that the preponderance of focus on the stresses of caregiving in the literature may itself

influence the outcomes that imply dementia caregiving families experience significant conflict. Siblings who provided instrumental support by assisting in the care of the parent, helped to increase the self-efficacy and decrease depressive symptoms for daughter CGs (Li, Seltzer, & Greenberg, 1999).

Qualitative Research on Dementia Caregiving and Family Systems

Grounded theory research conducted from a Bowenian family systems perspective explored the experience of five dementia caregiving families related to making choices about professional care for their loved one (Brodarick, 2014). Twelve individual or conjoint family semistructured interviews considered each family's history, ethos, patterns of conflict, interactions, and decision-making, before and after the loved one's dementia (Brodarick, 2014). In two participant families the primary CG was one or a team of offspring, the remaining three were spousal CGs. Though presented as grounded theory, the author provided only one theme across cases, gender as a definer of caregiving roles (Brodarick, 2014). The researcher suggested her findings support a systemic perspective when working with dementia caregiving families and a tentative theory that there is potential resilience in these family systems to deal with caregiving decisions (Brodarick, 2014). Further theory development may have been accomplished with more than five cases. The author noted that future studies might be better structured by interviewing all members separately and then the family together (Brodarick, 2014). The diversity in the caregiving experiences of these five families supports the notion that CGs, CRs, and their family systems are idiosyncratic (Montgomery & Kosloski, 2009).

La Fontaine and Oyebode (2014) completed a systematic synthesis of qualitative research that considered family relationships in dementia care. With criteria that required inclusion of the voice of the PWD, the authors were able to synthesize only 11 studies that

focused on how families experience dementia and how it impacts families (La Fontaine &

Oyebode, 2014). Of those, nine focused on dyadic family caregiving relationships, only one of

which was intergenerational. The remaining two studies (Purves, 2011; Ward-Griffin,

Oudshoorn, Clark, & Bol, 2007) are discussed below. While the dyadic relationship findings are

important, for the purpose of this review, only findings relevant to the family system are noted.

The authors found themes of shared history, both positive and conflicted that carried over into

dementia caregiving; relational strains and CG sense of entrapment due to past conflicts or the

current stress of caregiving; loss; and changes in roles and relationships which they deemed

"shifting sands" (La Fontaine & Oyebode, 2014, p. 1263). While not identified as themes, the

authors also noted that some participants blamed the dementia and some the PWD for problems,

with the latter reflecting more conflict, and that the family system can serve to support or weaken

the sense of self of the PWD (La Fontaine & Oyebode, 2014). This systematic synthesis reflects

the paucity of qualitative research focused on the dementia caregiving family system.

      The shifting roles and relationships in a dementia family were the focus of a narrative

analysis of interview data and naturalistic family conversations (Purves, 2011). The author noted

that narrative analysis had not previously been applied in dementia care to the family system, but

only to the individuals or dyads within the family (Purves, 2011). The researcher shared the

family's negotiations of the role of cook, previously that of the mother, as they adapted to her

Alzheimer's related declines (Purves, 2011). Other role changes included positioning the mother

as someone in need of protection or supervision, but the family grappled with ambiguity in these

areas, struggling to help her maintain her sense of self (Purves, 2011). The examined narratives

took place not long after the mother was given the diagnosis of Alzheimer's, thus much of what

the analysis revealed were negotiations around the acceptance and incorporation of AD into the

family (Purves, 2011). It is likely that the narratives would look different at a later stage requiring more direct caregiving. Still, this research provides some insight into how families work through the noted relational and role "shifting sands" noted above from the work of La Fontaine and Oyebode (2014, p. 1263). It is clear this family strove to position their wife/mother as a multifaceted woman who was only partly defined by her diagnosis of AD as they simultaneously renegotiated their own roles in the family (Purves, 2011). The author's suggestion that the findings support the work of the family system to reconcile who the PWD is becoming with who she has always been (Purves, 2011) is applicable as well to the system's sense of itself, i.e. reconciling the family system as it has been with what it is becoming in dealing with dementia. In both instances the dementia is only a part of the picture. Thus, there is a *person* with dementia (Purves, 2011) and a *family* dealing with dementia.

Ward-Griffin et al. (2007) suggested that in considering the family dealing with dementia, it is important to maintain a recognition of the continuity of the family system, rather than segment it into before and after dementia. Because they also eschewed segmentation by role, i.e., CR and CG, emphasizing a relational, essentially systemic approach, this study is included here despite its dyadic (Ward-Griffin et al., 2007) as opposed to CG focus. The authors found that cooperative or cohesive mother-daughter dyads tended to have strong family networks. Those that were less cooperative and cohesive had fewer resources (Ward-Griffin et al., 2007), suggesting that there may be a connection between the family system and resources available to caregivers. One daughter in a cohesive relationship with her mother described caregiving from a family systems perspective, "I was able to get lots of help from lots of family members" (Ward-Griffin et al., 2007, p. 26). Cohesive relationships evidenced growth in the relationship and in self-actualization in the mothers and daughters (Ward-Griffin et al., 2007), a

reality often missed in the literature that focuses on the burden of dementia. In broadening this perspective to the whole family dealing with dementia, the potential for growth and self-actualization in the face of dementia reflects the Bowenian perspective discussed in Chapter One. When the disrupting stress within a family is due to one member with dementia, questions arise as to how the family system copes with the stress and why in some families the primary CG does not experience accommodating the tension as excessive burden with isolation, feeling overwhelmed, and loss of control (BCFS, 2016h). The latter question has much to do with the characteristics of the CG and the circumstances of caregiving, but how caregiving was experienced by the dyads in this study was influenced by their family systems (Ward-Griffin et al., 2007). The authors noted that their research contributes to understanding of a complex dyadic CR-CG relationship (Ward-Griffin et al., 2007). Clearly, the family dealing with dementia is more complex than the caregiving dyad, yet the dyad and its constituent members cannot be fully understood apart from the system of which they are a part, supporting the need for research into this more complex phenomenon.

By sharing an autoethnography of her own caregiving experience, Polk (2005) demonstrated the potential for existing family dysfunction to complicate and degrade dementia caregiving. This research emphasized the need for multiple perspectives in understanding the mutual impacts of the family system and caregiving for a PWD (Polk, 2005). Polk (2005) suggested that an existing model of the caregiving stages of a family dealing with Alzheimer's (Wilson, 1989) may apply narrowly to functional families. Because members of less healthy family systems may be unlikely to participate or to be forthcoming in interviews (La Fontaine & Oyebode, 2014) and because most of the relevant research has been with convenience samples, it is plausible that much of what is known about dementia caregiving is biased toward functional

family systems. This calls for a richer understanding of the complexities of dementia caregiving within the family system, allowing for greater nuance of a wide spectrum of experience.

Polk's (2005) challenge that Wilson's (1989) model is too linear is validated by her example of a family in which members experience the stages cyclically, out of order and divergently from one another. Nonetheless, Wilson (1989) utilized interviews of 20 Alzheimer's CGs to identify from their lived experiences of the CRs' disease process, eight common stages. The first five stages cover the process from first suspecting dementia to obtaining and adjusting to the diagnosis (Wilson, 1989). The sixth stage is the decision about caregiving, the seventh is the caregiving experience itself, and the final stage is releasing the caregiving role (Wilson, 1989). While it may be too great a generalization to establish a model of caregiving stages from the experiences of 20 CGs, Wilson (1989) based the study on grounded theory whose purpose is to generate theory and utilized the largest recommended participant number for such research (McLeod, 2011). Because the family members in Polk's (2005) study did experience a number of Wilson's (1989) stages, it is not an exception to the stages so much as to the linearity of Wilson's (1989) model. Thus, the model may provide a useful lens through which to view the experience of dementia CGs, but as with models of human behavior and experience, does not prescribe the idiographic process of caregiving. Wilson's (1989) participants identified the preponderance of not knowing what to expect as a significant source of distress: "'You can't predict a thing! I wish I would have been told even that much'" (p. 43). Thus, the model can also be a source of tentative information and explanation for struggling CGs and their families.

Summary of the family system. It has been asserted that the literature on caregiving has been largely atheoretical (Raveis, Siegel, & Sudit, 1990) and, when theoretically driven, has oversimplified the complex experience (Nolan et al., 2002; Raveis et al., 1990). When

considering the limited research on caregiving and the family system (Qualls & Noecker, 2009), particularly dementia caregiving (Brodarick, 2014), this concern is more notable. The need to better understand the complexity of dementia caregiving suggests the benefit of qualitative research on the phenomenon from a family systems perspective as echoed by a participant in a dementia care service professional focus group, "More resources are needed to look at how to deal with family dynamics and how much added stress and anxiety it causes" (DiZazzo-Miller et al., 2013, p. 15). This understanding in turn can support those who work with or design interventions for CGs and their families as the family system may be an untapped resource to support CG resilience and adaptive abilities (McGoldrick, Gerson, & Petry, 2008).

Caregiving System

For this literature review, *caregiving system* entails interrelated parts of formal medical and support services, the caregiving dyad, and other informal CGs such as family and friends (See Figure 2). When *caregiving system* refers to only the formal system, it is noted.

In a mixed methods study, 45 CGs in the UK expressed a need for more information, emotional support, and interpersonal contact with the formal caregiving system, emphasizing better communication (Cascioli, et al., 2008). The need for more and better services may be more problematic when the CR has dementia as those caregiving systems appear to rely more on the household in which the PWD lives and less on outside supports than caregiving systems in which the CR is lucid (Birkel & Jones, 1989). Outside supports for dementia CRs were positively associated with CG satisfaction with life (Thorpe et al., 2009).

The latter research was correlational, so that while the authors suggested struggling CGs may be less likely to seek services for the CR (Thorpe et al., 2009), it is also possible that having poor access to services of all kinds may contribute to reduced satisfaction with life for CGs.

Additionally, because the use of home health care and/or in-home primary care was significantly associated with greater use of outpatient care (Thorpe et al., 2009), it may be that some CG-CR dyads are more open to a variety of services from the caregiving system. The uncertainty as to causality and to potential factors in degree of service use suggests that qualitative research may be needed to guide the use of services for dementia CRs and CG. Indeed, the authors noted the need for greater understanding of the association of variables and of the mechanisms behind their primary finding that CG life satisfaction was associated with CR receipt of outpatient services (Thorpe et al., 2009). The correlation between caregiving system services and CG well-being is not easily generalized from this study as it focused specifically on male CRs in the VA system and it did not include ancillary services (Thorpe et al., 2009) that might be greatly needed by dementia CGs. The authors did control for the fact that some participants had home care, but only indirectly for their use of non-VA outpatient services (Thorpe et al., 2009). Still, it is relevant to the current study in that it identified interrelationships between CG satisfaction, meeting of the needs of dementia CRs, and use of the caregiving system.

Access to formal supports. These interrelationships, as noted, may reveal that dementia CG well-being is influenced by access to support services from the formal caregiving system. The well-being of dementia CRs has also been shown to correlate with availability of such supports (Collins, King, & Kokinakis, 1994), yet CGs encounter barriers to such services. Being unaware of what services are available was cited by CGs and professionals working in the formal caregiving system as a barrier to accessing services (DiZazzo-Miller et al., 2013). While finding that 40% of 38 dementia CGs interviewed reported support services delayed or would have delayed nursing home placement, Collins et al. (1994) discovered that access, reported by 21% as availability and by 18% as cost, was a barrier to receiving needed services. Over 20 years

later, knowing where to find services and cost remained barriers (Feinberg & Levine, 2015).

Indeed, these authors asserted that the formal caregiving system is fragmented into service silos,

i.e., isolated services with little coordination or communication between them, and therefore

difficult for dementia CGs to navigate (Feinberg & Levine, 2015). The capacity to navigate that

fragmented system and to access services were important skills used by CGs for persons with

cancer (Schumacher, Stewart, Archbold, Dodd, and Dibble, 2000). A study designed to develop

theory based on qualitative research on transitions, including the transition to caregiving, found

that confidence in such transitions was evidenced by use of resources and growth in

understanding (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). However, recent

research has largely neglected addressing barriers to accessing support services from the formal

caregiving system for PWDs and their CGs (DiZazzo-Miller et al., 2013).

This neglect of addressing service access barriers in research is so even though Fortinsky

et al. (2002) laid the groundwork for measuring CG self-efficacy in obtaining services. From

interviews with 197 primary and secondary dementia CGs, their factor analysis identified two

self-efficacy factors, managing symptoms and use of "community support service[s]" (Fortinsky

et al., 2002, p. 153). Symptom management efficacy was negatively associated with

complications in mental and physical CG well-being; and community support service efficacy

negatively correlated with physical well-being (Fortinsky et al., 2002). Because the study was

cross-sectional, there is no assumption of causality (Fortinsky et al., 2002), but, in another cross-

sectional study, self-efficacy vis-à-vis mastery has since been demonstrated to moderate the

association between the subjective demands of dementia caregiving and depression and anxiety

symptoms (Pioli, 2010), suggesting, but not demonstrating, causality. Importantly, Fortinsky et

al. (2002) controlled for global competence and CR behavior symptoms in determining the

associations of the two self-efficacy factors with CG well-being. The sample may have been skewed toward greater efficacy in finding services since the participants were all recruited from calls made to a local AA helpline (Fortinsky et al., 2002).

Only three qualitative, two quantitative, and two mixed methods studies were found that addressed barriers to obtaining services for dementia CGs. One exception to the paucity of research was an exploratory, community-based qualitative study using semi-structured interviews of focus groups composed of 13 rural Canadian CGs and members of the formal caregiving system (Morgan, Semchuk, Stewart, & D'Arcy, 2002). Using constant comparison thematic analysis of the interview data, the researchers found a consistent theme of nonuse of formal caregiving services by CGs and categories of barriers to their use (Morgan et al., 2002). It was the members of the formal caregiving system rather than the CGs who spontaneously broached the subject of nonuse of community services in the focus groups, whereas the CGs were more concerned about access to a nursing home for the CR when needed and their own heavy stress and burden (Morgan et al., 2002). The identified barriers were: stigma and related denial by family and community; fear of loss of confidentiality especially because of the "fishbowl" (Morgan et al., 2002, p. 1134) of small communities; beliefs in self-reliance and that accepting care meant the CG had failed and that a nursing home admission would be next; lack of awareness about services; limited access to services due to distance and local providers with limited dementia knowledge; service costs that families could not or would not afford; whether CGs found the available services to be congruent with their needs; and challenges experienced by providers in delivering services (Morgan et al., 2002). This study was limited in scope as it specifically targeted rural populations, the majority of the CRs represented by the CG participants were in nursing homes, there was more input from the professionals than the CGs,

and there was great difficulty in obtaining CGs willing to participate (Morgan et al., 2002).

However, this study provides insight into what may be barriers to access to formal caregiving

services, uncovers the disparate focal concerns of CGs versus professionals, and is notable for

the way in which the disconnect between CG service needs and actual use arose organically

throughout the focus groups. The authors did offer potential solutions that could be guided by

further research to include case management that begins at the earliest stages of the dementia

caregiving journey, education for medical providers that is specific to dementia, and use of

technology in providing services. They also provided the important observation by home care

staff that the needs of PWDs appeared to be met, but not those of the CGs (Morgan et al., 2002).

An Australian mixed methods study of 20 dementia caregiving dyads provided further

insight into the gap between service needs and use and why CGs needs are often unmet (Stirling

et al., 2010). These CGs kept a diary of formal service use; participated in three semistructured

interviews related to service usage, experience of service providers and of caregiving, wants for

services, and socioeconomic situation; and completed measures of stress, operationalized as

psychological symptoms, subjective and objective burden relevant to CR function, cognitive

status, and dependency, and ratings of CG needs related to formal services (Stirling et al., 2010).

The measure of CG stress, a psychiatric screening tool, the GHQ-30, was not associated with

presumed sources of CGB, namely CR behaviors and dementia severity, but was correlated with

the ratings of need for more help from services, suggesting that unmet needs were more relevant

to CGB than the actual challenges of dementia caregiving (Stirling et al., 2010), Hours of

service use gleaned from the diaries was associated with dementia severity for only in-home

respite care, but not for any other type of service (Stirling et al., 2010). The qualitative data

provided insight into these surprising findings. CGs reported that in addition to cost, the effort

required and the guilt they experienced when taking a resistant CR to services out of the home

prevented their using those services (Stirling et al., 2010). The CGs described complicated lives

with sources of stress in addition to caregiving that measures of CR function and dementia

severity would not reflect, as well as stress caused by the process of seeking services itself

(Stirling et al., 2010). Noting that the formal caregiving system used assessments based on

presumed indicators of need to provide services, the authors suggested utilizing the CGs' stated

needs to guide service provision to more likely actually meet needs (Stirling et al., 2010).

A qualitative study of 32 CGs caring for PWDs living at home in the UK also found that,

for the formal caregiving system to provide effective support, it needed to elicit information from

CGs (Drennan, Cole, & Iliffe, 2011). The need to educe CGs perspectives was evidenced by the

participants reporting that they were rarely asked by service providers about dealing with CR

incontinence (Drennan et al., 2011). Hesitating to broach the subject themselves in deference to

the dignity of the CR, they often struggled to find their own solutions to deal with CR

incontinence as the problem progressed with the dementia (Drennan et al., 2011). Like the

Canadian rural CGs above who waited until a crisis to seek services (Morgan et al., 2002), these

CGs also hesitated to seek professional help in dealing with CR incontinence until a crisis such

as a hospitalization (Drennan et al., 2011). Even when CGs reached out to the formal caregiving

system for support and information in dealing with the problem, the providers lacked answers,

referred the CG to another unhelpful provider, and failed to recognize the significance of the

problem for the CRs' well-being and the CGs' distress, resulting in long ordeals seeking support

(Drennan et al., 2011). While not well studied, the problem of incontinence in PWDs has limited

evidence as a predictor of institutionalization (Haupt & Kurz, 1993; Luppa, Luck, Brähler,

König, & Riedel-Heller, 2008; O'Donnell et al., 1992) and as this study demonstrates contributes

to stress in CGs. This work is illustrative of how barriers to helpful services in dementia

caregiving exist within the caregiving dyad and the formal caregiving system.

Research in Singapore further demonstrated the relevance of including CG needs and

beliefs about available services in actual service use (Liu, Eom, Matchar, Chong, & Chan, 2016).

Based on longitudinal data from 1,416 caregiving dyads, with a 43% response rate from a

random sample, this study considered associations of service use to CG ratings of formal

services based on quality, convenience, social connectedness, and affordability (Liu et al., 2016).

After referral to community- or home-based services, approximately one half of caregiving

dyads used the referred services initially and approximately one quarter were using them six

months later, with those who were not using services having a lower perception of them in all

four categories (Liu et al., 2016). While controlling for CR and CG characteristics known to be

related to use of the formal caregiving system, the researchers found that quality, convenience,

and affordability predicted service use at the time of referral and that affordability was the

strongest predictor of service and was the only category significantly related to service use at six-

months follow-up (Liu et al., 2016). This study has limited generalizability to U.S. dementia

CGs based on its focus on all diagnostic categories of CRs, the particularly strong cultural sense

of responsibility to care for one's own family in Singapore, the common use of domestic workers

as a potential source of support in the home (Eom, Penkunas, & Chan, 2017), and the differential

advances in that nation to establish models for community care and an agency to direct

integration of care (Liu et al., 2016). Despite these limitations, the large size of the study, its

longitudinal nature, its unique focus on CG perception related to service use, and the finding that

offering services based primarily on CR characteristics without addressing CGs' needs reduces

service use merit its attention here. The authors suggested that further services would be more

beneficial to caregiving dyads if they were integrated, holistic, and include monitoring and support for CG well-being (Penkunas, Eom, & Chan, 2016).

      Benefits of formal support. One way effective support has been shown to be beneficial is its association with a decrease in CGB (Majerovitz, 2001). Standard measures of CGB and depression in 54 coresident spouse dementia CGs were not directly associated with formal or informal supports (Majerovitz, 2001). However, in multiple regression analyses, the researcher found that the formal support of paid CGs buffered the negative association between the memory and behavior problems of CRs and CGB. There were no buffering effects of formal support on CG depression and of informal supports on CGB or CG depression (Majerovitz, 2001). Reasons for no apparent benefit on these outcomes when the CR is presenting memory and behavior problems may be low statistical power (Majerovitz, 2001) or the possibility that informal support can be both helpful and conflictual (Kwak et al., 2012; Merrill, 1996; Rabins et al., 1982; Semple, 1991; Suitor & Pillemer, 2007), statistically cancelling out the benefits of helpful informal support. There was no accounting for the possibility that CGs who chose to hire outside help may have differed systematically from those who did not. For the analyses, the researcher defined informal support as the number of care helpers and did not address the quality of the help as perceived by CGs (Majerovitz, 2001). Additionally, informal versus formal support was operationalized simply as whether there were paid CGs (Majerovitz, 2001), thus making conclusions regarding formal versus informal support only tentative. Notably, the author suggested future research should distinguish between formal and informal supports. This study did provide a look at the little studied phenomenon of the impact of formal supports on CG well-being (Majerovitz, 2001), providing insight into how dementia CGs experience working within the formal caregiving system.

Despite this tentative evidence that formal support might improve CG well-being, Japanese researchers found no decrease of CGB related to formal social supports, except for the support of primary care physicians (PCPs; Shiba, Kondo, & Kondo, 2016). This study controlled for relevant demographics, caregiving factors including level of care, dementia severity despite not focusing exclusively on dementia caregiving, and, notably, hesitation to access formal care (Shiba et al., 2016). With less than a 50% response rate, the researchers used data from nearly 3,000 CGs who responded to a regional survey and completed multiple regression analyses that revealed informal social support, but not the number of supporters, was associated with decrease in CGB (Shiba et al., 2016). As noted, CG perceived social support of the PCP was associated with less CGB, but despite controlling for level of care and hesitance to enlist formal supports, higher CGB was associated with perceived social support by care managers (Shiba et al., 2016). This cross-sectional study cannot provide evidence of causation, but it is curious that experiencing social support from care managers was reported by CGs with higher levels of burden, independent of the level of care or dementia severity (Shiba et al., 2016). The authors logically surmised that this correlation could be because high levels of burden may have precipitated seeking out care managers (Shiba et al., 2016).

Tales of two nations. Clearly, access to and benefit from the formal caregiving system relate in a complex way to the dementia caregiving dyad, supporting the need for qualitative research to shed light on how dementia CGs experience the caregiving system. The need for a more systematized approach to formal caregiving supports (Feinberg & Levine, 2015) and the suggestion by the authors of the above study in Japan that further research is needed to clarify the relationship between the experience of caregiving and formal support (Shiba et al., 2016), confirm the need for formal CG supports to meet verified needs. Further research regarding

caregiving and formal support for dementia CGs is particularly needed as the work by Shiba et al. (2016) was not dementia specific. For that reason, the following discussion considers the development and evaluation of a formal program to address the needs of dementia CGs in the UK. Because the current research is in the US, the state of American dementia-specific formal support is considered.

The British experience. While the Admiral Nurse Service was founded in 1990 to provide dementia-specific community nursing support for CGs in the UK (Maio, Botsford, & Iliffe, 2016), the nation was still relying primarily on psychiatric community nurses with little training in dementia for dementia CG support in 2001 (Pickard & Glendinning, 2001). In a qualitative study of 12 older coresident CGs of CRs with moderate to severe dementia, based on observation and on semistructured interviews regarding the formal caregiving system of the CGs and the assigned community nurses, case studies were developed (Pickard & Glendinning, 2001). Three primary factors were found to be challenging by the CG: nighttime behaviors and incontinence, lack of opportunities to get relief from caregiving, and the stress of giving intimate personal care, which suggested important needs still to be met by the caregiving system (Pickard & Glendinning, 2001). The few who had any respite care, primarily adult daycare, did not feel it was good for the CR, yet felt obliged to accept the service because they had been told it was necessary for their own well-being (Pickard & Glendinning, 2001). The community nurses provided advice and emotional support but no hands-on care when they were contacted by a distressed CG (Pickard & Glendinning, 2001). The interviewed community nurse recognized the particular stresses of dementia caregiving, but their role did not entail meeting identified needs directly or via arranging support services. Both the CGs and nurses verbalized a sense that the CGs were largely on their own and the CGs had little idea what the role of the community nurses

was (Pickard & Glendinning, 2001). While the nurses indicated trying to include the CGs in

identifying and meeting needs, the authors suggested that there was a lack of CG input in

planning the CRs' care, a necessity for more research on the CG-nurse provider interaction, and

a need for better access and connection to formal services to meet CG identified challenges

(Pickard & Glendinning, 2001).

Shared care planning was the focus of an autobiographical narrative study of the Admiral

Nurse service (Keady et al., 2007), providing a picture of this program, described by dementia

CGs as help with "practical things" (Dementia UK, 2016a, p. 9), emotional support, and answers,

i.e., information (Dementia UK, n.d.; Pickard & Glendinning, 2001). The website associated

with the Admiral Nurse service evidenced a comprehensive program that was relational, with

caregiving dyads largely having one assigned Admiral nurse (Dementia UK, n.d.). Within the

context of a formal caregiving system perceived as lacking transparency and tending toward

attitudes of professional superiority over lay CGs, one of the authors experienced the services of

the Admiral Nurse service while caring for her mother with dementia (Keady et al., 2007).

Likely because the mother was in residential care and the father had recently died, the Admiral

Nurse provided primarily emotional support and the care plan she collaboratively developed with

the CG focused on helping her process her grief and develop confidence in the caregiving role

(Keady et al., 2007) rather than the practical supports noted above to be needed by dementia

CGs. What this study did provide was a glimpse at how the Admiral Nurse service strove to be

guided by the needs of the CG, CR, and the family (Keady et al., 2007). By addressing the

experience of informal and formal dementia caregiving from a narrative perspective, the authors

provided a shared construction of the experience and identified the benefits of a truly systemic

approach that values the dementia family caregiving system within the larger caregiving system

(Keady et al., 2007).

Effectiveness of the Admiral Nurse program was addressed via feedback from CGs related to the standards on which the service was founded, but not via any measurable outcomes and without directly addressing whether the founding principles are congruent with the needs of CGs (Maio et al., 2016). While only having a 30% response rate to the 685 questionnaires sent out, the survey revealed high levels of satisfaction among respondents for the abilities (82%), interventions (83%), and rapport (97%) of Admiral nurses (Maio et al., 2016). It might also be helpful to specifically address the experience of new CGs, to see if the service helps in the transition to caregiving and that of longtime CGs to gain a long-term perspective of the service.

There have been concerns there are not enough Admiral Nurses, evidence of satisfaction with the service, and limited knowledge of how effective it is (Bunn, Pinkney, Drennan, & Goodman, 2013). Those concerns, satisfactions, and lack of sufficient knowledge have extended from 1990, when the Admiral Nurse service was founded, to 2001, when it was still little known or used, to 2004 when, with only 50 Admiral Nurses, it was noted to be beneficial, to the current decade, with approximately 200 Admiral Nurses (Kelly, 2017). There is ongoing work to determine its effectiveness and find areas for improvement (Dementia UK, 2016b). Thus, with nearly three decades of providing a unique dementia CG focused service valued by CGs, the UK still is working to determine its value. However, in the U.S. little has been done to attempt such a widespread dementia specific program let alone evaluate it, as evidenced by the 2017 introduction of a bill to initiate a dementia infrastructure (Building Our Largest Dementia Infrastructure for Alzheimer's Act [BOLD], 2017).

Comparative American experience. Notably, in the US, the recommendations related to dementia services have primarily come from the private sector, particularly the AA (Fazio, Pace,

Maslow, Zimmerman, & Kallmyer, 2018). In 2015, it was reported that there were 43.5 million

informal CGs in the US, yet in the previous year, only 700,000 individuals caring for CRs of all

ages and with all diagnoses received direct services from the federal initiative, National Family

Caregiver Support Program (Administration for Community Living, 2019). Informational

support to find other services was given to an additional 1.3 million (Administration for

Community Living, 2019). Specifically, for CRs with dementia, a review of U.S. federal health-

related agencies provides evidence of a fragmented system of recommendations focused on

factual information, initial diagnosis of Alzheimer's, residential care standards, the need for

advanced directives and other legal issues, and end of life concerns, with limited guidance for the

formal caregiving team to best serve CRs and CGs (National Institute on Aging, n.d.; U.S.

Department of Health and Human Services, 2016). There is a webpage for CGs that emphasizes

the need for self-care, describes support services (many of which must be paid by the individual),

and provides a phone number to call for information with acknowledgment that, "it's okay to

seek help whenever you need it" (National Institute on Aging, 2017, para. 1). Interestingly,

some of the more comprehensive guidelines for formal caregivers to be able to support both CRs

and CGs in a list provided by the U.S. Department of Health and Human Services (2016) were

developed by the British health services (National Institute for Health and Clinical Excellence,

2007).

The Alzheimer's Association offers local and national online services, primarily

information, referral, and e-support communities (AA, 2018a, 2018b). They have a national

telephone hotline and local support groups (AA, 2018a). AA-Central Ohio Chapter provides

consultation by phone, e-mail, or, notably, in person (AA, 2018b). It is not clear from AA's

website if all chapters offer care planning/case management (AA, 2018a). The three-part

mission of AA is to support all those affected, by inference to include PWDs, families, and CGs, to promote prevention, and to advance research toward treatment and a cure (AA, 2018a). The latter goal, in particular leads to a strong focus on fund raising.

CGs in the US can hire a geriatric care manager at $50–200 per hour plus expenses and receive some of the care planning, coordination, referrals, and other services similar to what the Admiral nurses provide, but the availability and dementia specialization vary by location (AgingCare, n.d.). An alternative to geriatric care mangers is the U.S. system of Area Agencies on Aging (AAA). These agencies have a broad mandate to establish regional services for older Americans based on local needs that encompass nutritional support such as Meals on Wheels, adult protective services, health promotion, assistance with staying in or returning to the work world, transportation, homemaking services, some in-home care, training for CGs, and case management (Fox-Grage & Ujvari, 2014; National Association of Area Agencies on Aging [n4a] & Miami University Scripps Gerontology Center [MU], 2017). Helpful AAA services for dementia CGs and CRs may be scarce, with each AAA offering an average of 22 services, 30% providing no care planning, and just over half making any evidence-based services for CGs available (n4a & MU, 2017).

A mostly rural county in central Ohio provides an example of the limited AAA resources for CGs. That county had a total 2012 budget for AAA services of 7.2 million dollars for 26,276 persons over the age of 60, with zero dollars provided for service coordination unless in the Medicaid programs which accounted for 6.7 million of the total dollars (Central Ohio Area Agency on Aging [COAAA], 2018). Caregiver support in that county was one of eleven services that received federal Older American Act dollars, totaling $329,108 (COAAA, 2018). Assuming the county is statistically similar to the nation, just over one quarter of older adults, or

6,569 individuals, would have at least one disability and approximately 57%, or 3744, of those

persons would have assistance from an informal CG (Johnson & Wiener, 2006). Thus, the Older

American Act dollars would provide just $87 per CR for CG services if none of the other ten

services were provided in the county. While the AAA program is for all older Americans, it is

clearly not funded to serve all CGs. Rightfully AAAs are required to give priority to poor and

marginalized individuals as reflected in budgets that are supported by only 39% federal dollars

and over a quarter from Medicaid (n4a & MU, 2017), yet many CGs are left to fend without this

potentially valuable service and, for dementia CGs, with few opportunities for dementia-focused

services.

Although created 17 years before the Admiral Nurse Service with the 1973

reauthorization of the Older Americans Act, the AAA system with its much broader mandate,

offers dementia specific services only if individual AAAs have the funds and opt to do so (n4a &

MU, 2017). A report of AAAs surveyed in 2016 only described activities to promote making

communities more livable for older Americans and/or PWDs, but not to provide caregiving

support (n4a & MU, 2017). Thus, in the U.S., dementia CRs and CGs may receive dementia

specific caregiving support dependent on whether they live where the regional AAA has chosen

such a focus or a local agency has received a grant from the National Family Caregiver Support

Program (Administration for Community Living, 2019) and implemented a dementia specific

program; have access to funds to pay privately or are on Medicaid; or have the knowledge,

wherewithal, and time to piece together services across agencies, i.e. the CG is able to act as

their own case manager. That a primary source of services for older Americans provides

dementia specific services inconsistently (n4a & MU, 2017) may contribute to the perception of

insufficient information as a barrier to needed services for dementia caregiving dyads in the US.

Need for information and communication. Despite the plethora of factual information on websites such as those of AAAs and AA, a frequently reported reason for not receiving needed supports in dementia care is lack of information (Feinberg & Levine, 2015). Needing more information was associated with increased CG stress (Stirling et al., 2010), and CG self-efficacy was associated with confidence that one could attain answers from the formal caregiving system (Fortinsky et al., 2002). Lack of information regarding life transitions appears to be an inhibitor of successfully negotiating transitions such as becoming a CG (Meleis et al., 2000).

Recognizing that lack of knowledge and ineffective communication related to services for PWDs were barriers to receiving those services and that existing services, as with the U.S. AAAs, were not dementia specific, Germany developed Dementia Care Networks (DCNs) with a primary focus on information dissemination strategies (Heinrich et al., 2016). Assuming these networks can only successfully coordinate dementia care if relevant knowledge is effectively disseminated, the researchers conducted a qualitative study to determine the effectiveness of DCNs at managing knowledge needed by CGs, CRs and all those in the caregiving system (Heinrich et al., 2016). Semi-structured interviews were conducted first individually with the coordinators of 13 regional DCNs chosen because of their successful status, without clarification of what deemed them successful, and then in groups with professional staff working within those DCNs (Heinrich et al., 2016). Applying thematic analysis to the interview data, the researchers described how knowledge was managed within the networks and distributed to CGs and CRs and to other members of the caregiving system external to the DCNs (Heinrich et al., 2016). Frequently cited barriers to knowledge management were insufficient resources, rivalrous conflicts between provider agencies within the networks, inaccessibility of external providers, particularly PCPs, and the lack of time CGs had to participate in DCN information dissemination

efforts (Heinrich et al., 2016). Most relevant to the present study were the findings related to distributing needed knowledge to CRs and CGs. Eleven of the 13 DCNs interviewed had formalized structures in place to disseminate information to caregiving dyads via brochures and handbooks, public service events, notices in local newspapers, and on the radio, a telephone hotline, and the websites of the DCNs (Heinrich et al., 2016). The authors identified a successful strategy used in one DCN of piggybacking on an existing national service that assesses older adults in need of home services to disseminate knowledge of the DCN services and also promoted the use of case managers to overcome some of the barriers (Heinrich et al., 2016).

A psychoeducation program in Canada for CGs provided immediately after a dementia diagnosis improved self-efficacy in caregiving, the ability to plan for future care needs, awareness of how to attain answers and services from the formal caregiving system, and coping strategies in an RCT (Ducharme et al., 2011). Of the 111 participants in the study, the 49 in the control group received usual care including connection to local services and to the Alzheimer's Society, and the 62 in the experimental group received seven 90-minute individual educational modules, two of which specifically addressed planfulness and what formal support services were available and how to access them (Ducharme et al., 2011). Although the groups were not equivalent, the researchers controlled for baseline scores in their analyses (Ducharme et al., 2011). There were statistically significant differences between the control and experimental groups and, notably, the intervention accounted for 22% of the difference in feeling prepared for caregiving and 21% of the difference in knowledge of services (Ducharme et al., 2011). Although long-term outcomes are unknown, since data was collected only post-program and at three-months follow-up, this psychoeducation program, inductively designed based on the requests of a pilot group of dementia CGs, provides evidence that provision of information is of

value, at least at the beginning of caregiving (Ducharme et al., 2011).

That finding was echoed by the participants in a phenomenological focus group study in the US of CGs, early stage CRs, and professionals experienced in dementia care, looking at the experience of CGs in accessing the formal caregiving system across the spectrum of dementia severity (DiZazzo-Miller et al., 2013). The broad findings were that CGs experienced frustration at not knowing what resources are available, not receiving information to find those resources or being overwhelmed with too much information at the beginning of caregiving, and not knowing what or whom to ask (DiZazzo-Miller et al., 2013). Those findings were so even though participants were already connected with the local AA (DiZazzo-Miller et al., 2013), a provider of information (AA, 2018a). A common theme was the desire for a single source of information (DiZazzo-Miller et al., 2013), yet dementia care managers who are in such a role, as previously noted, appear to be of uncertain benefit to CGs (Shiba et al., 2016). Also, as noted, in the US, CGs can hire a geriatric care manger privately (AgingCare, n.d.) or rely on the fragmented system (Feinberg & Levine, 2015). Early-stage CGs in particular experienced a lack of clarity as to what information and referrals they needed yet knew that education to guide them through the journey of dementia caregiving was essential (DiZazzo-Miller et al., 2013). Later-stage CGs continued to find difficulty navigating the formal caregiving system and appeared to have learned to seek support from family, friends, and the Internet (DiZazzo-Miller et al., 2013). This increase in reliance on the Internet belied the preference CGs expressed for in person support. The professionals, who were part of the caregiving system, agreed that dementia CGs need information and education to understand what the formal system offers and how to obtain needed services (DiZazzo-Miller et al., 2013). The authors concluded that information alone would not suffice because the CGs in the study were looking for applied knowledge that would fit their

needs and lamented that the formal caregiving system meant to support the CG-CR dyad should be an added source of frustration (DiZazzo-Miller et al., 2013).

Information about formal services available was also cited as an important need by Welsh CGs who were interviewed in a mixed methods study (Cascioli et al., 2008). For many of these CGs, lack of information began early in the process when they were not told a diagnosis to match the CRs' cognitive declines and continued with lack of information about the CRs' conditions once diagnosed with a form of dementia. Further, many were not given referrals or needed information regarding available services and expressed a need for education related to the CRs' diagnoses and to caregiving (Cascioli et al., 2008). Unlike the participants in the study by DiZazzo-Miller et al. (2013), these CGs felt they needed more information at the time of diagnosis (Cascioli et al., 2008). When discussing their experience of accessing formal caregiving services, the interviewees offered a wide variety of barriers to services, but most endorsed difficulty related to communication and a desire for more supportive, personal visits. That these CGs at times felt unheard, marginalized, and even abandoned by the formal caregiving system (Cascioli et al., 2008) is of significance in the current discussion. The results of the study, in keeping with its finding that CGs are eager to have their ideas and needs heard, were used to guide government policy in the region (Cascioli et al., 2008).

Even though policies and programs addressing the need for dementia caregiving support and information were already in place when a focus group study considered the needs of U.K. dementia caregiving dyads, including informational and communication needs, the participants expressed more frustration than satisfaction with the formal caregiving system (Sutcliffe, Roe, Jasper, Jolley, and Challis, 2015). The CGs and CRs echoed themes noted above of needing a single source for information and finding too much information soon after diagnosis to be

unsettling (Sutcliffe et al., 2015). These participants also encountered communication from the formal caregiving system that was insensitive, dismissive, or unidirectional without the CGs or CRs feeling heard (Sutcliffe et al., 2015). They found that service providers in the formal caregiving system, including PCPs, often lacked awareness and knowledge of the dementia experience. This research offered a unique perspective in that one third of the active participants were CRs (Sutcliffe et al., 2015). For those CRs and their CGs, the gap they described between how the caregiving system was supposed to work and what they experienced was detrimental to their quality of life unless they serendipitously encountered helpful providers. The authors suggested that incorporation of information and referral services into primary care might be an effective way of accomplishing the desired single source for dementia caregiving information (Sutcliffe et al., 2015).

The literature cited above provides an unclear picture of what information is helpful to dementia CGs and CRs and when it is most helpful, particularly near the time of the initial diagnosis, even though a 2003 study of 100 dementia CGs attempted to answer the questions of the content and timing of information for CGs (Wald, Fahy, Walker, & Livingston, 2003). These authors noted the calls at that time for more systematized dissemination of information to dementia CRs and their CGs and for purposeful inclusion of CGs in that process (Wald et al., 2003). Following a pilot study, the researchers developed a questionnaire utilized for semi-structured interviews to determine, from qualitative and quantitative data, what information at what point in the caregiving journey and from what source would have been helpful (Wald et al., 2003). Findings included benefit to the caregivers of categorizing information; desire to receive information directly from professionals, from organizations such as AA, and in writing; and preferences for timing the informational categories as follows (Wald et al., 2003). CGs preferred

at initial diagnosis definition of dementia, pharmaceutical treatments, and behavioral and

psychiatric symptoms of dementia; at a subsequent appointment, what to expect as dementia

progresses, options for services, and guidance for crisis situations; at a later appointment

available support groups, knowledge of benefits to which they were entitled, and financial and

legal matters; and at a still later appointment, information related to impacts of dementia

caregiving on CGs, alternative treatments, and psychological therapies (Wald et al., 2003). The

researchers did not indicate if the psychological therapy was for CRs, CGs or both, provide

clarity as to the timing of later appointments, or give the percentage of CGs' preferred categories

except at the time of initial diagnosis (Wald et al., 2003). Their emphasis of the top three

categories at that time does not reflect a close fourth category or two other strong categories,

including information on support groups, which may be salient to some CGs and particularly to

CRs who at an earlier stage can benefit from support groups (Wald et al., 2003). It thus may be

most important to note from this study that CGs are overall eager for knowledge, that they vary

in how much they want at the beginning of the caregiving journey, that it is helpful to offer

information categorically, and as the authors recommended, that the guidelines should be applied

with flexibility to meet CG needs specifically (Wald et al., 2003).

Helpful professionals within the formal caregiving system have the potential to offset

tensions in the caregiving dyad, similar to triangles in a family system (BCFS, 2016i), as they

form a triadic relationship with CR and CG (Adams & Gardiner, 2005). There is also potential

within such a triad for any two members to collude against the other (Biggs, Phillipson, &

Kingston, 1995). Inclusive communication is a means of avoiding such collusion (Adams &

Gardiner, 2005). The dementia caregiving triad, moving beyond a dyadic construct, is not a tight

three-person mini system, but rather a readily expandable, dynamic grouping that incorporates

other family and caregiving system members (Adams & Gardiner, 2005). Figure 3 demonstrates the triad, its expandability, and its occurrence within the societal system. Adams and Gardiner (2005), using a social constructivist perspective, stated that members of the formal dementia caregiving system can learn skills to inclusively communicate to dementia CRs and their CGs in ways that are enabling rather than disabling. They also advocated assessing CR-CG interactions to help CGs learn to communicate in more empowering ways. While providing particular focus on the often-lost voice of the PWD, the authors provided narrative examples from their own practice with dementia CGs and CRs (Adams & Gardiner, 2005).

The role of medical providers. Medical providers for the PWD are an important part of the formal caregiving system and in conjunction with CR ad CG make up a triad in need of further research (Fortinsky, 2001). Considering the previously noted fragmentation, there has been a call to extend a systemic perspective to the caregiving system such that medical providers, particularly PCPs, need to include CGs and their needs in providing for CRs (FCA, 2014; Feinberg & Levine, 2015). Not only might this promote receipt of needed services to keep the CR well and at home longer, but it can also give providers a more accurate picture of the CR's situation and condition (Feinberg & Levine, 2015), and thus promote better communication. While the value to CGs of the PCP appears to vary based on the severity of dementia symptoms (DiZazzo-Miller et al., 2013), the literature reflects the reality that PCPs are the most likely professional in the formal caregiving system to have regular contact with the caregiving dyad. That PCPs are the most probable regular contact with the dyad and that they were the only source of formal support associated with decreased CGB for the Japanese CGs above (Shiba et al., 2016) makes the call for a systemic primary care model that incorporates CGs (FCA, 2014; Feinberg & Levine, 2015) more noteworthy. The call is in keeping with the U.S. core primary

care values that define it as an information intensive relationship that equates physical and

mental well-being (Donaldson, Yordy, Lohr, & Vanselow, 1996).

Thus, medical providers, particularly PCPs, are a potentially important gateway to

appropriate information and services for PWDs and their CGs. Utilizing primary care as an

information gateway can potentially be accomplished via the existing trend toward integrated

care, following the recommendations from the National Research Council to locate care

coordination in PCP practices (Donaldson et al., 1996). Such integrated care will require

addressing previously noted barriers to effective PCP-CR-CG triads, including PCPs with

insufficient expertise in dementia care (Sutcliffe et al., 2015), others in the formal caregiving

system having difficulty accessing PCPs (Heinrich et al., 2016), and assumptions about CGs by

PCPs, such as that they will assume the caregiving role (Välimäki et al., 2012) or that they are

functioning well and having their needs met (Riedel et al., 2016). An example of such barriers in

action occurred during an RCT of a program designed to link consultation services with PCPs

(Fortinsky, Kulldorff, Kleppinger, & Kenyon-Pesce, 2009). Of the physicians in the study, 73%

did not discuss with the CGs and CRs the care plans developed by the services and placed in the

medical chart (Fortinsky et al., 2009). This lack of communication demonstrates the importance

of defining and developing integrative care from a patient and family CG perspective, which is

likely to more effectively meet the needs of specific complex populations such as PWDs (Kodner

& Spreeuwenberg, 2002). Integrated care that takes advantage of established ongoing

relationships that PCPs have with PWDs has the potential to be a much needed one-stop shop for

harried CGs to obtain information and referrals (Sutcliffe et al., 2015).

PCPs and other medical providers were insufficient in providing such information and

referral in a study of 307 dementia caregiving dyads (Jennings et al., 2015). These dyads were

referred to a dementia management program and, based on assessment at initiation of services, it

was clear that the existing reliance on medical providers was not effective (Jennings et al., 2015).

These CGs completed measures of depressive symptoms, stress, and CR symptoms at intake;

CRs were measured for cognitive status and functional ability at intake; and 227 of the CGs

completed a survey prior to intake rating the referring physicians' awareness of the CRs'

cognitive status, the degree to which the CG had been informed about dementia care, and the

CGs' self-efficacy related to dementia caregiving and to obtaining support services (Jennings et

al., 2015). Based on the preintake survey, 65% of these CGs had not been told future

expectations related to dementia behaviors, 61% were not advised on managing dementia

problems, 75% did not know about available services, and even more, 81%, were not informed

as to how to obtain services (Jennings et al., 2015). While it is possible some CGs did not absorb

provided material and communications for a variety of reasons, it is clear that their need for

knowledge and guidance had not been met. It is unlikely that the CRs were newly diagnosed and

the providers had not had opportunity to give needed information as the cognitive scores are

suggestive of moderate dementia and the measure of functional status indicated, on average,

notable loss of abilities (Jennings et al., 2015). Only 35% and 32%, respectively, of these CGs

experienced confidence they could handle caregiving stress and the challenges of caring for a

PWD, explaining the overall average low self-efficacy score (Jennings et al., 2015). The need of

the CGs for support, information, and guidance in caregiving was notable as 70% reported

problems with aggression and agitation in the PWDs (Jennings et al., 2015). Nearly as many

reported nighttime behaviors, which were rated as severe by 22% of the CGs (Jennings et al.,

2015). Aggression and agitation and nighttime behaviors were rated as the most highly

distressing CR behaviors to the CGs (Jennings et al., 2015). Although the CGs verbalized more

confidence in the helpfulness of referring physicians who were geriatricians, there were no

statistically significant differences by type of medical provider in CG self-efficacy or ratings on

the preintake survey. This is noteworthy considering that 57% of the referring providers were

geriatricians (Jennings et al., 2015), who receive specialized training in medical issues common

in older adults (American Geriatrics Society, 2018), such as dementia.

Noting that PCPs are often the first to encounter PWDs prior to diagnosis, a Dutch study

of 107 suspected cases of dementia explored what diagnostic information PCPs provided, to

whom it was given, and the accuracy of the diagnosis (van Hout, Vernooij-Dassen, Jansen, &

Stalman, 2006). This prospective observational study utilized self-report by the PCPs and a

follow-up diagnostic examination of 93 participants who completed the study, by experienced

professionals in a memory clinic to validate accuracy of the PCP diagnoses. Results revealed a

false positive rate of 20% and a false negative rate of 33% despite self-reported high compliance

with required diagnostic guidelines, (van Hout et al., 2006), reinforcing the above concern that

PCPs are insufficiently informed regarding dementia (Sutcliffe et al., 2015). The PCPs were

more likely to reveal the diagnosis to both CRs and CGs if symptoms were more severe,

suggesting that hesitance to tell the caregiving dyad a diagnosis of dementia may be less about

discomfort in giving bad news as the authors asserted (van Hout et al., 2006) and possibly related

to uncertainty of diagnosis. The authors suggested further work from a qualitative perspective

could add to the knowledge base regarding PCPs reasons for withholding a diagnosis of

dementia (van Hout et al., 2006). Significantly, the PCPs were nearly twice as likely to share a

diagnosis with CGs than with the patient being give the diagnosis, and of interest to the current

study, guidance from the PCP regarding what to expect related to the diagnosis occurred in 42%

or less of the cases depending on the type of information (van Hout et al., 2006). While this

study was conducted in one European country over a decade ago (van Hout et al., 2006), it does demonstrate potential pitfalls in relying on PCPs to deal with PWDs and their caregivers at the time of diagnosis without integration into the larger caregiving system.

The challenges, however, are not limited to primary care. Research that considered 403 Alzheimer's caregiving dyads seeking services in a neurology clinic for the CRs revealed that when the physicians rated the CGs for emotional, physical, and time constraints and their need for advice, help in caregiving, and treatment of physical or emotional problems, they underestimated the severity of the needs and challenges of caregiving and the physical and emotional problems that CGs experienced (Riedel et al., 2016). Of CGs who met criteria for a major depressive disorder, the physicians rated 60% as having mild or no depressive symptoms (Riedel et al., 2016). Using an interrater reliability definition of level of agreement (McHugh, 2012), the physician ratings demonstrated no agreement with CGs related to their need for advice about Alzheimer's (Riedel et al., 2016). The physicians and CGs agreed only minimally related to the CGs' time burden and psychological comorbidity. They did demonstrate strong agreement related to the CGs' reported physical comorbidities, perhaps reflecting a logical bias toward recognizing medical issues. The physicians, whose patients were the CRs, not the CGs, provided ratings without conducting diagnostic interviews or medical examinations of the CGs (Riedel et al., 2016) so that expectation of correctly identifying diagnoses is unrealistic. It is notable that so few recognized depressive symptoms, the severity of the impacts of caregiving, and the need for advice and information. Relevant to the previous discussion of CGs' need for information and communication, the physicians' overestimation of the degree to which the CGs were informed about dementia is striking. The authors suggested that education at the beginning of caregiving on awareness and self-monitoring for depression and regular depression screening of CGs would

be beneficial; and emphasized the importance of recognizing the medical providers seeing

dementia CRs as potentially important resources for addressing CGB (Riedel et al., 2016).

The idea that medical providers can play such a role is reflected in the promotion of

integrated care in the literature (Donaldson et al., 1996; Kodner & Spreeuwenberg, 2002).

Despite the push for greater integration of care, a Canadian report reviewed recommendation for

addressing dementia needs and found of six countries and the EU, only the US did not specify

collaboration and integration of dementia services (Champlain Dementia Network, 2013). The

role of government, as a part of the societal system, in meeting the needs of dementia caregiving

dyads is discussed below in Societal Systems.

Qualitative studies of the caregiving system. While qualitative studies have already

been discussed, this section closes with a look at qualitative research that considers perspectives

of CGs and members of the formal caregiving system and the relationships between them.

A single case study using descriptive analysis provided understanding of the lived

experience of one spouse dementia CG as she worked with the formal caregiving system to care

for her husband and make decisions regarding relinquishing care to residential placement

(Winslow, 1998). Collected data were observation notes and responses to open-ended interview

questions by the spouse CG, a leader of her Alzheimer's support group, and the director of her

husband's adult daycare, with the four developed themes confirmed via member checking

(Winslow, 1998). This CG utilized no formal services until she had been caregiving for 6 years

and began by attending the support group, which gave her relief, emotional sustenance, and

helpful ideas to ease caregiving, including the concept of adult daycare (Winslow, 1998).

Though she verbalized pride in her ability to provide care and extreme guilt and sadness when

she first left her husband at daycare, the CG verbalized that the experience was very positive for

her husband, became an opportunity for her to relax and accomplish noncaregiving functions, and prevented her from placing him in residential care sooner (Winslow, 1998). The CG received confirmation that placing him in residential care was acceptable and necessary from all members of the formal caregiving system, her own medical doctor, her husband's psychiatrist, the daycare director, support group members, and the group leaders, who observed that CGs sometimes seek permission to institutionalize (Winslow, 1998). Placement of her husband brought the CG relief, freedom, expectations that she would adjust and be able to again live her life, certainty that it was the right decision, and a continued-though-different caregiving role (Winslow, 1998). It also brought, sorrow, guilt, and no relief from poor sleep (Winslow, 1998). The themes identified and reflected in this caregiving story were developing the need for formal supports, experiencing a sense of community during the caregiving journey, benefitting her own well-being when she was sure her husband was doing well, and transitions (Winslow, 1998).

The process of developing a caregiving support network experienced by the preceding CG is illustrative of the themes identified in the data from diaries and semistructured interviews of 13 dementia CGs in England (Egdell, 2012). This researcher identified three routes by which CGs develop a support network, the first being organic, which, like the CG above, occurs as needs change and one service, such as her support group, links and encourages expanding to other needed services (Egdell, 2012). CGs who engaged in guided routes typically had sufficient resources, took charge of developing their support network, and exhibited greater self-efficacy in navigating the formal caregiving system based on knowledge of dementia and available resources (Egdell, 2012). Lack of knowledge of the likely need for and availability of formal caregiving support led some CGs to develop their networks by chance, sometimes prompted by a crisis (Egdell, 2012). The quality of CG relationships with PCPs influenced some of their

experiences of support network development, again highlighting the pivotal role of medical

providers as previously discussed. Sadly, the CGs in this study reported that their support

networks not only expanded with progression of CR dementia, but at times, particularly informal

supports, receded and fragmented, due to inability or unwillingness of friends and family to

continue in supportive roles (Egdell, 2012), emphasizing the importance of the formal supports.

Because of the significance of the formal dementia caregiving system, it is valuable, and

unfortunately rare, to consider the perspectives of those who work in it as occurred when 41 such

workers participated in focus groups and three in individual interviews (Jansen et al., 2009). It

has been suggested that members of the formal caregiving system may better recognize patterns

of service use than dementia CGs caught up in the grind of their personal caregiving experiences

(Morgan et al., 2002). Unlike CGs whose prevalence of insufficient knowledge about dementia

caregiving is well-documented, 89% of these participants agreed at least mildly that they were

sufficiently prepared for dealing with dementia (Jansen et al., 2009). Results indicated concerns

about insufficient dementia training for workers in their field generally (Jansen et al., 2009),

possibly reflecting overconfidence, but likely those who volunteered for the study differed from

all workers in their level of interest in PWDs. The study used a team approach to thematic

analysis of the flexible interviews and identified broad themes regarding dementia services of

availability, the existence of facilitators and barriers, and acceptability (Jansen et al., 2009).

Barriers were lack of financial and personnel resources, which participants believed resulted in

greater expenses such as hospitalization; mismatch between available services and CG needs or

the nuances of dementia care; not knowing what is available leading to chance connection to

services as Egdell (2012) observed; and lack of a systematic infrastructure (Jansen et al., 2009).

Where systems functioned well via a version of case management and bridging of services,

availability was facilitated (Jansen et al., 2009). Participants felt their work was hampered and the caregiving dyads suffered because of lack of time and poor systemization (Jansen et al., 2009). Less fragmented, more affordable care that seeks to meet needs of both members of the dementia caregiving dyad were suggested as ways to increase acceptability of services (Jansen et al., 2009). Other recommendations included family directed care underpinned by services deemed essential, formalizing services and education related to incontinence, specific help with bathing, seeking insight as to care needs for the CG and not just the PWD, and respecting the CG as an expert in their own care situation. A side theme in several studies above, was overtly identified by these participants who noted that services early in the dementia caregiving journey along with more consistent early diagnosis and physician referral might prevent caregiver burnout and waiting for crises to receive services (Jansen et al., 2009). For the current study, it is noteworthy that the authors observed that emotional support for the challenges of caregiving and the ongoing grieving process CGs may encounter is given short shrift (Jansen et al., 2009). While Jansen et al. (20019) aimed to consider the perspective of the formal caregiving system, the participants gave privilege to the voices of the CGs.

Such privileging hints at the importance of the relationship between dementia CGs and those who provide formal services, which was the subject of a grounded theory study of 18 CGs and the key worker each CG identified (McGhee & Atkinson, 2010). The theory developed provided explanation of the development of the relationship and its impact on the dementia caregiving situation (McGhee & Atkinson, 2010). The relationships were enhanced when workers respected both members of the dyad. CGs appreciated the workers, and the workers were able to share worthwhile knowledge with the CGs (McGhee & Atkinson, 2010). Enhanced relationships increased CGs' confidence in their caregiving role, promoted opportunities for

them to openly share their thoughts and feelings, and enabled workers to more effectively meet

the dyads' needs (McGhee & Atkinson, 2010). These relationships sometime developed into a

therapeutic alliance characterized by a sense of warmth and mutually held goals of care (McGhee

& Atkinson, 2010). When appreciation and respect were lacking, the key workers' roles were

unclear to both parties or CGs were unwilling to relinquish any aspects of care, the relationships

suffered (McGhee & Atkinson, 2010). These less healthy relationships and the enhanced

relationships tended to be self-perpetuating (McGhee & Atkinson, 2010). The authors suggested

that these insights would be beneficial to incorporate into training for those who work in the

formal dementia caregiving system (McGhee & Atkinson, 2010).

Based on the belief that one's identity is forged via interactive language, discourse

analysis was used with data gathered from interactions between psychiatric nurses and family

CGs and by the researchers' interviews of CGs (Adams, 2000). It was assumed that in

conversation people can categorize, cast identities on, position, and even subjugate self and

others and that, as the nurses and CGs conversed, they were negotiating meaning and identities

(Adams, 2000). The author asserted that even when policies promote mutual respectful

partnerships amongst CGs and members of the formal caregiving system, the specifics of the

interactions between individuals will shape identities and determine decision-making authority

(Adams, 2000). Awareness of this concept can be used to guide those who support dementia

CGs to empower them and in particular PWDs who tend to be ignored in terms of decisions

about their own care (Adams, 2000). Understanding of relationships between dementia CGs and

members of the formal caregiving system has the potential to inform public policy (Adams,

2000) and, as noted in the preceding study, to shape training of those who are employed in the

system (McGhee & Atkinson, 2010), issues of relevance to the societal system discussed below.

Summary of the caregiving system. Throughout this section, there are references to the

need to have collaborative, integrated, accessible services and well-communicated information

that are relevant and specific to the needs of individual caregiving dyads, yet the current formal

dementia caregiving system in the U.S. is fragmented (Feinberg & Levine, 2015; National

Institute on Aging, n.d.; U.S. Department of Health and Human Services, 2016). The call to

> a shift in the prevailing paradigm . . . in order to come to consider caregivers as potential
>
> clients of the health care system, with support needs of their own, rather than as resources
>
> to be exploited by the system (Ducharme et al., 2011, p. 493)

is apropos. While initiatives with promise exist (Boustani et al., 2011; Galvin, Valois, & Zweig,

2014; Jennings et al., 2016), if this situation is to improve it will need to be systematized to be

readily accessible to meet dementia caregiving needs and flexible to meet those needs

germanely. In dementia care, providing idiosyncratically relevant services is complicated by the

long and dynamic trajectory of Alzheimer's disease and other causes of dementia. Qualitative

research, such as the current study, can provide insight into the idiosyncratic needs of CGs and

CRs while providing reflections that may be relevant to changes needed in the caregiving

system.

Societal System

Caregivers, family systems, and the caregiving system exist within and mutually

influence the larger societal system. Previous discussions of the stigma of dementia, insufficient

public awareness, the impact of governments and public policies, and the stress CGs experience

balancing multiple roles, provided initial insight into dementia caregiving within the societal

system. For the purpose of this discussion, *societal system* is loosely defined to include local,

national, and global societies as well as subcultures within those societies. Dementia caregiving

dyads and those who advocate for their needs reciprocally interact with the societal system.

Social networks. Consideration of the multiple layers of dementia CGs social networks

provided understanding of their complex association to CG psychological well-being (Cohen,

Teresi, & Blum, 1994). This study considered the impact of informal family and nonkin

relationships, formal relationships with members of the caregiving system, and institutional

relationship with, for instance, places of worship and support groups (Cohen et al., 1994). The

researchers conducted analyses to see whether these types of relationships directly had effect on

or, via mediation or moderation, influenced the association of caregiving stressors with CG

psychological distress (Cohen et al., 1994). Findings related to this outcome concluded that only

places of worship had direct effects and that the impact of caregiving stressors was mediated

only by contact with places of worship and by practical supports from the formal network

(Cohen et al., 1994). No network variables moderated the effect of caregiving stressors. It is

intuitive that, as dementia severity worsened, CG contact decreased with places of worship and

increased with support groups (Cohen et al., 1994) since CR behaviors can make attendance at

formal services more difficult, while increasing the need for support from others in the trenches.

However, a puzzling finding was a decrease in CG contact with the formal network as CR

dementia severity increased (Cohen et al., 1994). There is little to explain this lessening of

network contact or why, other than places of worship, social networks appeared to provide little

effect on CG psychological distress. The latter null finding could be due to low power as many

statistical tests were conducted on data from 58 caregiving dyads (Cohen et al., 1994). This

study's reliance on primarily spouse CGs limits its generalizability to other CGs whose informal

networks may be quite different.

Valuing independence could explain the low association of social networks to dementia

CGs' psychological well-being in the previous study and indeed a discourse analysis of

interviews with 48 New Zealand CGs found a value of self-sufficiency promoted independence

whereas dependence was equated with being burdensome (Breheny & Stephens, 2012). While

this research was done with CGs of CRs across diagnostic categories, its relevance to

understanding the influence of the societal value of independence merits its inclusion.

Foucauldian discourse analysis, with the aim of discovering how talk legitimates or challenges

social structures, was conducted with data from semi-structured interviews around the topics of

social and family connections and family change, clarifying how these CGs constructed their

own identities and social connections (Breheny & Stephens, 2012). These discourses

emphasized independence as a moral virtue that supersedes asking for or receiving help, even if

legitimate needs are thus unmet. Only desperation would lead one to accept help, which was

equated with demeaning dependence and thus being burdensome (Breheny & Stephens, 2012).

The authors noted the irony that choosing not to have needs met could lead to greater

dependence. Independence as a value sometimes conflicted with the value of family

responsibility to provide care, yet dependence on a family member was at times situated as

counter to dignity and respect and thus purchased care was preferable (Breheny & Stephens,

2012). The discourses regarding independence were mostly focused on the future when the CG

comes to need care for self. When the CGs focused on their caregiving role, they reframed the

dyadic interactions relationally, as *being there*, an obligation for some and a treasured experience

for others (Breheny & Stephens, 2012). Perhaps there is a stronger value of independence in

New Zealand than in the US, but this concept provides explanation for why CGs often do not

take advantage of available help as observed in the discussions of the caregiving system.

Because this study was not dementia specific, it is not possible to know how the inevitabilities of

dependence in dementia would impact beliefs about independence for CGs and PWDs. These

authors asserted that when societies promote independence as a value, responsibility for well-

being is shifted from society to older adults, disproportionately negatively impacting those who

are disenfranchised, particularly with lifelong poverty or health problems (Breheny & Stephens,

2012). They propose an alternate discourse of interdependence in which family members and

society share responsibility and autonomy is valued, but not pseudo independence that ignores

legitimate needs (Breheny & Stephens, 2012).

   The role of government and public policy. Ideally, shared responsibility will shape

public policy (WHO & ADI, 2012), but it is not typical that voices of CGs, let alone those of

PWDs, are integral to policy development (Schulz & Eden, 2016). There are, however,

exceptions as noted in the Welsh study above, the results of which were used in government

policy planning to develop training initiatives, expand services for early-onset dementia, improve

communication with service providers, and provide emotional support workers for dementia CGs

(Cascioli et al., 2008). Citizen-based policy has continued to develop in Wales with a goal of a

better quality of life for PWDs via early diagnosis, ready access to services and information,

more integration of care, and better training in "dementia supportive communities" (Alzheimer's

Society [AS] & Welsh Assembly Government, 2011, p. 4). The vision of inclusion where PWDs

and CGs are viewed as full members of society, has grown into a comprehensive action plan

developed out of ten consultation events in 2016 and 2017 and an online survey that sought input

from PWDs and immediate family and friend support systems (AS & DEEP, 2017; Welsh

Government, 2017). The most fundamental aspects of the strategy developed include improved

rates of diagnosis; access to a multirole support worker able to advocate, coordinate, and give

practical and emotional assistance soon after diagnosis and throughout the dementia journey;

PWD-involved training for healthcare and social service workers in dementia; and special

attention to the needs of those with early-onset dementia, minorities, those with other disabilities,

or those who live alone (AS Cymru, 2017). Implementation of evidenced-based practices,

including assistive technology (AS Cymru, 2017), stepped approaches, music, and aromatherapy

(Brechin, Murphy, James, & Codner, 2013), are encouraged as is evaluation of the effectiveness

of existing services; and recommendations without evidence base are challenged (AS Cymru,

2017). The comprehensiveness of this plan prevents its thorough consideration here, but it

provides an example of a multilevel person-centered social model of policy development that

resists the medical model and privileges the perspectives of PWDs and those who care for them

(AS Cymru, 2017).

 U.S. initiatives. While the U.S. system of AAA has been detailed above, there are two

new national initiatives worth noting here and a need for awareness that this country currently

has no dementia strategy comparable to that in Wales. That the US was unique among eight

nations in not recommending collaboration and integration of dementia services (Champlain

Dementia Network, 2013) has the potential to change with these policies, one which has been

enacted and one which is proposed.

 On the federal level, the US has enacted a law effective January 22, 2018, entitled the

Recognize, Assist, Include, Support, and Engage Family Caregivers Act of 2017, or RAISE, to

develop a national strategy for supporting family CGs and establish an advisory council (Cilmi,

2018a). The bill requires development of a person-centered strategy targeting all levels of

government, communities, and providers to plan and coordinate services with focus on

"performance, mission, and purpose" (RAISE, 2018, p. 2). RAISE (2018) mandates

incorporation of assessment; provision of training, education, and information; development of

respite services; and attention to issues of finances and caregiver employment. Notably, performance, mission, and purpose are not defined, no funds are provided, an initial strategy is required in 18 months, and, unless renewed, the bill terminates in three years (RAISE, 2018). However, it emphasizes evidence-based and innovative models; promotes systematization, including use of existing government resources to disseminate information; and mandates a means of public input into the strategy development (RAISE, 2018). The advisory council is to consist of no more than 15 members with at least one each of CGs, older adults who needs services, persons with a disability, and veterans. Providers, workers, officials, and employers are to also be on the council (RAISE, 2018). Although more CRs and CGs are not precluded and a person-centered approach is mandated, this does not leave room for privileging their voices as was done in the Welsh example. The initial task of the council does present promise regarding reducing fragmentation in the current efforts to meet caregiving needs. A required report at one year should shed light on the role and effectiveness of existing federal programs; the challenges of CGs and how they are currently addressed; and the impact of informal caregiving on federal programs, including Medicare and Medicaid (RAISE, 2018). The report is also to provide recommendations for better coordination of federal and state programs (RAISE, 2018).

Pending legislation, BOLD, if enacted, has potential to reduce fragmentation of dementia services specifically via establishment of Alzheimer's centers of excellence (BOLD, 2017). While of great import, the portions of this bill that address prevention and treatment of Alzheimer's disease itself are beyond the scope of this current study. BOLD (2017) includes education of private and public power brokers and the general public in dementia related issues; data collection and analysis for ongoing policy guidance; advancement of evidenced based interventions for PWDs and CGs; awareness of underserved populations; promotion of early

diagnosis; and increasing CG support. BOLD (2017) appropriates 37 million dollars for

implementation which contrasts with its statement that the annual costs of Alzheimer's disease

are anticipated to be over one trillion dollars by 2050.

RAISE and BOLD follow the Healthy Brain Initiative which began in 2005 (Cilmi, 2017)

as a national road map for maintaining cognitive health (The Pioneer Network, 2012) and the

establishment of the National Plan to Address Alzheimer's Disease, in the National Alzheimer's

Project Act (NAPA) of 2011. The Healthy Brain Initiative was launched in 2005 to establish a

research-based expert consensus on how to develop further research on prevention,

communications, policies, and data tracking in support of maintaining Americans' cognitive

health, with attention to CG needs (The Pioneer Network, 2012). It was the source of the

caregiver module in the Behavioral Risk Factor Surveillance System (BRFSS) discussed below

(The Pioneer Network, 2012). NAPA, with its advisory council was the structure upon which

the RAISE act was based (Cilmi, 2018a). It was required to be an integrated plan coordinating

public and private research and services within the US and internationally with goals related to

treatment and a cure (Assistant Secretary for Planning and Evaluation, 2012). NAPA was also

required to address support for PWDs and CGs, fight stigma, and educate potential providers

(Assistant Secretary for Planning and Evaluation, 2012). NAPA's goals are currently guiding

federal spending, with a 414 million dollar increase in the 2018 budget for dementia research at

the National Institutes of Health (Cilmi, 2018b). Despite the Healthy Brain Initiative and NAPA,

BOLD was needed because of a prominent lack of attention to the public health urgency of

addressing dementia (Cilmi, 2017).

Other contributions on a national level include National Institutes of Health funding of a

large multistate RCT of a mental health treatment for dementia CGs (Schulz et al., 2003) that is

considered below in the discussion of mental health treatments for CGs. Additionally, the

Centers for Disease Control and Prevention (CDC) included a caregiving module in the state-

administered Behavioral Risk Factor Surveillance System (CDC, 2018). That module was

intended to increase knowledge about CGs and their experience of stressors, while distinguishing

dementia from nondementia CGs. Including the BRFSS caregiving module was optional for

states (CDC, 2018), resulting in spotty use until recently. No more than 10 states used it from its

inception in 2009 through 2013 and no states utilized it in 2014 (CDC, 2019). However, all but

five states used the caregiver module in 2015 through 2017 (AA, 2016a).

Together, RAISE and BOLD are a move toward guiding public policy with

understanding of the CG system (Eom et al., 2017), standardization of information provided to

CGs (Egdell, 2012), development of a systematized care infrastructure (Jansen et al., 2009), and

input from those most affected (Schulz & Eden, 2016). Input from those in the trenches, CGs,

CRs as they are able, and providers from the formal caregiving system, will be essential in

developing effective programs (Feinberg, 2014a; Schulz & Eden, 2016). Federal efforts have

been multiple in the current century, yet urgency is still lacking as is systematization, as

evidenced by the need for dementia infrastructure (Cilmi, 2017), leaving the fragmentation to be

addressed. Whether systematization and urgency have been effectively addressed by the 50

states is not clear in the literature and beyond the scope of this literature review. However, with

the mobility of the U.S. society, the reliance of older American on federally administered

Medicare for health care, and the scope of the problem of dealing with care for PWDs, it is

reasonable to expect national guidance to prevent further fragmentation into 50 separate systems.

Systemization from a longitudinal perspective to provide accessible, available services with

community buy-in is a struggle on the state level as well, as experienced in developing policies

for broader statewide behavioral health services (Lampl, 2018).

Financial aspects. Interestingly, one of the above pieces of legislation comes with

funding and one does not, although the dollars for BOLD are relatively minimal. That public

policy must consider costs is a given, but if initiatives are guided primarily from this perspective

without awareness of what older adults want and the realities of complex life situations, the

actual needs of PWDs and their CGs, including those with limited resources, may be overlooked

(Reinhard et al., 2015; Sanborn & Bould, 1991). It is not unreasonable that the societal system

should be expected to develop effective supports for CGs and cover some of the costs of doing

so given the 470-billion-dollar value to society of the work that they do (Reinhard et al., 2015).

Because the assumption has been made in much of the literature that when PWDs remain

at home rather than going into a nursing home it saves society money (Reinhard et al., 2015;

Sanborn & Bould, 1991), it is important to consider empirical evidence of the assumption. How

to calculate differential costs requires determining whether the value of CGs' work is part of the

equation (Hurd, Martorell, Delavande, Mullen, & Langa, 2013). From a broader perspective of

all societal costs, what CGs contribute becomes part of the equation, but then questions arise

such as whether to utilize a per hour value or the cost of lost wages, and whether to include time

spent supervising a PWD or just direct care hours (König et al., 2014). Also, there do not appear

to be studies to determine more complex indirect costs such as lost tax revenues, spending, and

investments when CGs leave the work force or expenses from declines in CG health.

König et al. (2014) considered the value of CGs' contributions without the more complex

indirect costs when they studied the differential costs of home versus nursing home care in

Germany. Surprisingly, these researchers found that community care cost more for these 176

PWDs than nursing home care. CGs provided their hours of informal care, the costs of hospital

stays, other medical care and supplies, professional in-home care, and nursing home care (König

et al., 2014). The 48 PWDs who were residing in a nursing home had more severe dementia, but

no significant difference in comorbid diagnoses, suggesting cost differences were unlikely to be

related to costs of other conditions. When the researchers controlled for cognitive status,

sociodemographics, and comorbidities, medical costs did not differ significantly and nursing

home care was significantly costlier by $13,584 annually (König et al., 2014). That figure was

calculated without the value of informal caregiving in the equation. When calculated with the

German minimum wage applied to direct informal caregiving hours, including supervision hours,

home care was more expensive by $45,060 (König et al., 2014). When lost productivity was

considered rather than caregiving hours, home care was more costly by $34,339 per year (König

et al., 2014). These data and the fact that informal caregiving accounted for 52.8% of total costs

for these home dwelling PWDs emphasize that whether to include the value of informal

caregiving is highly salient to the question of the cost of dementia care. Results should be

generalized cautiously to other countries as they were based on German social security and

health care systems and German wages (König et al., 2014). The study demonstrates that what

CGs provide is not free to a society and provides insight into how dementia caregiving costs

differ by whether the CR lives in the community

　　　While not seeking differential costs by whether PWDs live in the community, annual

expenses of dementia care were calculated for the US with and without the value of informal

caregiving (Hurd et al., 2013). Included in these calculations were self-reported out of pocket

medical expenses, hospital and nursing home stays, Medicare and nursing home expenditures,

formal home care, and informal caregiving value. The latter was calculated based on either lost

wages, adjusted for CGs' likelihood of being in the workforce, or the prevailing wage for the

time spent in caregiving, deemed replacement cost. Calculations, controlling for comorbidities

and relevant demographics such as age, race, and gender, demonstrated that dementia is

associated with $28,501 per person expenses without inclusion of informal care costs and

approximately half of this was due to nursing home expenses (Hurd et al., 2013). Controlling for

the same factors, dementia was associated with $41,689 in costs with lost CG wages included

and $56,290 with per hour cost of replacing CGs included. Extrapolations based on population

data provided estimates of societal costs of dementia care, demonstrating that 126 billion more

dollars would be spent in the US in 2020 if informal caregiving hours were replaced with paid

providers (Hurd et al., 2013).

A study in Indiana considered the differential medical care and Medicaid expenditures

between PWDs who lived in nursing homes and those receiving Medicaid paid services in the

home via waiver (Sands et al., 2008). Unlike the research by Hurd et al. (2013) and König et al.

(2014), the value of informal caregiving was not included (Sands et al., 2008). The researchers

controlled for comorbidities, insurance status, marital status, and level of health care use prior to

entering a nursing home or beginning the Medicaid waiver program. The home-based PWDs

were significantly more likely to have a hospital admission and to seek emergency department

care than those in nursing homes, resulting in greater hospital costs for the in-home PWDs.

However, the primary source of differentiation in costs was the long-term care service itself, i.e.,

nursing home care or in-home waiver services (Sands et al., 2008). The dementia expenses for

the PWDs living in nursing homes was significantly greater by $20,256 annually in 2008 dollars

than for the home-based PWDs, even though the in-home PWDs also incurred Medicaid paid

long term care costs via waiver and had the greater hospital expenses. The costs for the home-

based CGs rose through the year of the study whereas the expenses of those in nursing homes

remained steady (Sands et al., 2008). The authors offered no plausible explanation and, as the

study ended, no way to know if the trend toward greater in-home costs might have continued,

negating the between group differences. The groups were nonequivalent by size as 90% were in

nursing homes and there was no indication of the role of informal caregiving (Sands et al., 2008).

Although this research leaves questions, it provides evidence that, even when the public sector

covers some of the costs of care at home for PWDs, there are potential savings of public dollars.

Preceding researchers noted that there are nonmonetary and impractical-to-measure

monetary costs to dementia care (Hurd et al., 2013). However, in aggregate, these findings and

data reinforce the importance of addressing the financial aspects of dementia care and echo the

idea that the services provided by CGs are invaluable (Reinhard et al., 2015).

Qualitative research. Policy development that recognizes CG value, embraces the

voices of PWDs, and incorporates shared responsibility were essential components of the subject

of a discursive analysis aimed at developing an international framework through which to

understand quality of life in dementia and systematic evaluation of related policies and services

(Banerjee, Willis, Graham, & Gurland, 2010). Spoken and written words by a total of 312

contributors from six international conferences that included professionals, PWDs and CGs were

analyzed using open coding by two researchers to support trustworthiness of their findings

(Banerjee et al., 2010). The researchers found five intertwined domains that impact quality of

life for PWDs under three broad societal themes of "Public Attitudes and Understanding . . .

Government and Social Policy . . . [and] Funding for Services" (Banerjee et al., 2010, p. 251).

The five domains were health in all realms; verbal and nonverbal communication centered on the

needs of the PWD; social and physical environments; good care and support by well-trained CGs

to CRs and by well-trained providers to both members of the dyad; and autonomy, identity, and

spirituality with the latter three most heavily emphasized, particularly the final domain (Banerjee et al., 2010). Findings that are particularly relevant to dementia CGs were the preeminence of love; the underlying assumption that CG quality of life is tied to that of CRs; and the imperative to take time for effective communication, for CRs to make choices, and for provision of care (Banerjee et al., 2010). This framework developed uniquely from a societal and public health perspective (Banerjee et al., 2010), has potential to shape systematic evaluation and planning of services and policies to better meet the needs of PWDs and their CGs in meaningful ways that enhance quality of life. As noted previously in the discussion of Adams's (2000) discursive work around CG identity formation, empowerment can occur individually and through policy development in ways that enhance the life of the caregiving dyad. Such understandings, as these studies have provided, are the goal of qualitative research.

Summary of the societal system. It is clearly a challenge to address dementia caregiving from a societal perspective. The topics have ranged from the multibillion dollar value of dementia CG services to society (Hurd et al., 2013; Reinhard et al., 2015) to the preeminence of love in dementia care (Banerjee et al., 2010). Still, the need for comprehensive, systematized care, long called for (Coletti, 1997), stems both from financial costs and the meaning of the word *care* itself, which a just society cannot ignore (Heschel, 1975; Vatican Radio, 2013). The current study, intending to provide understanding of dementia CGs' needs, can inform policies that better meet those needs.

Conclusions Regarding the Interdependent Systems

A Welsh CG identified the interdependence of the caregiving and family systems, noting that when "fumbling through" (Cascioli et al., 2008, p. 24) the confusion of finding services, family conflict resulted. The framework developed by Banerjee et al. (2010) demonstrated the

multiplicity of domains in which PWDs and their CGs live out the caregiving journey. The

Welsh CGs' experience demonstrates how the systems mutually impact one another. At the core

of all the systems is a person with dementia, relying on a caregiver, who needs support from the

family, caregiving, and societal systems. In the process of better understanding CGs' needs, the

current research can also help to support PWDs.

The Dyadic Relationship

The CR at the core is in a unique relationship with a CG, forming the caregiving dyad.

Research related to the dyadic relationship in dementia care is sparse. Perhaps that is not

surprising in that there is a tendency to treat PWDs as their disease rather than as persons

(Banerjee et al., 2010), potentially leading to less emphasis on there being two people in the

relationship. Thus, in addition to a study on mother-daughter dementia caregiving dyads, a study

focused on nondementia caregiving dyads is considered here because its findings demonstrate

the importance of the dyadic relationship for CG outcomes. The participants of both included

studies were primarily European American, further reflecting that this topic is understudied, as

no research on the dyadic relationship in other racial and ethnic groups was found.

These dyadic relationships do not spontaneously occur in caregiving, but develop from

previously existing relationships (Coletti, 1997). One researcher sought to find the association of

preexisting quality of mother-daughter relationships on the daughter's experience of dementia

caregiving (Coletti, 1997). For a convenience sample of 52 coresident dyads, a negative

correlation was found between the perceived quality of precaregiving relationships and CGB,

while role captivity, measured as a dichotomous variable based on responses to related questions,

was not associated with CGB (Coletti, 1997). The measure of relationship quality had seven

subscales, three of which were associated with CGB. These subscales are affective expression,

entailing level and appropriateness of emotional expression; affective involvement, which

considers relational balance related to absent or intrusive involvement; and role performance

based on capacity to integrate, clarify, and adapt roles within a relationship. In a hierarchical

regression analysis, affective expression and affective involvement remained statistically

significant, accounting for 8% and 3% of variance in CGB, respectively. Other significant

variables that predicted CGB in this analysis were CR cognition and bother—annoyance related

to caregiving tasks and CR behaviors—measured on a four-point Likert scale (Coletti, 1997).

Because the predictor variable *bother*, had potential for collinearity with CGB, a second multiple

regression analysis was run without it. In that model the only significant dyadic subscale was

affective expression which accounted for 15% of the variance in CGB. Because of convenience

sampling, sample size, and focus on only one type of CG dyad (Coletti, 1997), results should be

generalized cautiously. The author surmised that negative or positive attribution related to

bothersome CR behaviors may partially explain how the quality of the past relationship

influences CGB (Coletti, 1997), which is supported by a more recent finding that meaning in

caregiving is related to the quality of the dyadic relationship (Quinn, Clare, McGuinness, &

Woods, 2012). These findings provide further reason to promote early diagnosis, as PWDs can

work to improve relationships with their families while they are still cognitively able.

Relational aspects of caring, including conflict, stress due to CR dependency, affection,

and satisfaction with caregiving, along with objective caregiving factors were assessed for their

relationship to outcome variables of CG strain, defined as self-perceived caregiving related

disruption in multiple domains, and self-reported caregiving-related negative emotions in 98

dyads (Sheehan & Nuttall, 1988). Seventy-five percent of these CGs were children or children-

in-law of the CR and over 80% were female (Sheehan & Nuttall, 1988). Questionnaires at

initiation and four-months follow-up provided data revealing that affection for the CR was negatively associated with CG strain and with negative emotion; satisfaction with caregiving was not associated with strain, but was negatively associated with negative emotions; and interpersonal conflict with the CR was positively associated to CG strain and to negative emotions (Sheehan & Nuttall, 1988). After ruling out multicollinearity of variables and guided by existing research, the variables were entered into a multiple regression analysis, revealing affection did not contribute significantly to outcomes and CR conflict with the CG accounted for 29% of CG strain and 47% of CG negative emotion (Sheehan & Nuttall, 1988). Since the data were cross-sectional (Sheehan & Nuttall, 1988), it is not possible to determine the direction of association. It is possible that CG strain and negative emotions lead to conflict with the CR. While dated and not dementia specific, this study provided strong evidence that the quality of the dyadic relationship is an important factor in caregiving outcomes and worthy of further inquiry.

Together, these studies provide evidence that the quality of the preexisting and current dyadic relationship influences the experience of caregiving. While this seems obvious given the fact that most CGs choose their role because of at least basic concern for the well-being of the CR, Coletti (1997) demonstrated that negative family interactions and patterns that shaped the dyadic relationship remained relevant. The capacity to express emotion appropriately, to establish balance in relational involvement, and to attribute intent in CR behaviors without false assumptions (Coletti, 1997), affection for the CR, and management of interpersonal conflict with the CR (Sheehan & Nuttall, 1988) are all likely to improve the relationship and caregiving outcomes. In offspring dementia caregiving, the CG-CR relationship is complex and can be better understood by bringing CG lived experiences to light as the current study intended.

Caregiver Identity

The dyadic relationship in dementia caregiving is one of role transformation that impacts the identity of the CG's self, situated in an idiosyncratic situation (Montgomery & Kosloski, 2009). Montgomery and Kosloski (2009) suggested that lack of attention to the variability of the caregiving experience by individual situations and over time was a reason that efforts at CG support have not been highly successful. This research, again not dementia specific, sought to delineate a caregiver identity theory, asserting that caregiving is a series of role transitions shaped by expectations of family and societal systems (Montgomery & Kosloski, 2009). *Identity* was defined as role identity in relation to the CR such that when initiating or adding new tasks to caregiving a previous identity as daughter, son, spouse, etc. incorporates new behaviors that are in conflict with the CG's previous identity in the relationship, creating incongruence with sense of self, a possible source of CGB (Montgomery & Kosloski, 2009). These authors proposed a phased process of accommodating self-identity to the caregiving role with transitions occurring when the incongruity between role activities and identity becomes too uncomfortable and necessitates a change in role identity to ease the discomfort. For instance, the offspring-older parent role does not entail bathing the parent so that when that becomes needed, the dyad may feel uncomfortable and the CG will need to move toward an identity that is closer to caregiver and farther from child. If unable to make that transition in identity, a potential care crisis may occur (Montgomery & Kosloski, 2009). The authors asserted that this understanding can guide referrals for services by timing them to meet idiosyncratic needs that arise during times of unnegotiated transition of identity around a care need (Montgomery & Kosloski, 2009). An example applying the author's assertion would be for the offspring unable to bathe a parent because of not identifying as a caregiver. In such cases, paid help could resolve the discomfort

and prevent institutionalization of the CR (Montgomery & Kosloski, 2009). While the authors

do not address the concept, cognitive flexibility is suggested in their writing related to

incongruence between identity and the demands of caregiving and the resultant need to change

self-perception, behaviors, or beliefs about caregiving (Montgomery & Kosloski, 2009).

Cognitive flexibility thus may be a worthwhile target of treatment for distressed CGs. This

article does not claim to provide empirical evidence of their theory, although it is based on prior

research (Montgomery & Kosloski, 2009), but one author's subsequent work below provided

support (Savundranayagam & Montgomery, 2010).

A convenience sample of 358 spouse CGs referred by their case managers completed

telephone interviews (Savundranayagam & Montgomery, 2010). While this study was not

dementia specific, 80% of these CRs had some cognitive deficits, and over half were diagnosed

with dementia. Control variables included gender and years spent caregiving, predictor variables

were the amount of ADL assistance needed and behavior problems of the CR, and outcome

variables were affective, relational, and objective burden (Savundranayagam & Montgomery,

2010). It was hypothesized that measures of role discrepancy as spouses and CGs would mediate

the associations of predictor and outcome variables. Identity discrepancy and problem behaviors

directly predicted greater burden in all three realms and identity discrepancy partially mediated

the relationship of problem behaviors to the three outcome variables (Savundranayagam &

Montgomery, 2010). ADL assistance predicted only objective burden directly, but its impact on

affective and relational burden was fully mediated by role discrepancy, which the authors

suggested meant that ADL care was not in itself stressful but became so when it was outside the

CG's perceived role (Savundranayagam & Montgomery, 2010). Problem behaviors, however,

appear to be inherently stressful and almost by definition challenge the spouse role. Their

unpredictability makes it harder to prepare for and incorporate managing behaviors into the perceived caregiving role (Savundranayagam & Montgomery, 2010). While applying only to spouse CGs, this study does support the preceding caregiver identity theory.

When the role incongruities are not resolved, there is risk of role engulfment for dementia CGs that can result in a loss of identity (Skaff & Pearlin, 1992). Based on the belief that one's sense of self is shaped and maintained by interaction and feedback from others, the authors asserted that dementia caregiving, with its tendency to decrease opportunities for social interaction outside the dyad and the decrease in the CR's capacity for reciprocity and feedback, presents significant risk of loss of self (Skaff & Pearlin, 1992). This need for social interaction and feedback could explain surprising findings that being an employed CG, despite the stresses of juggling multiple responsibilities, does not consistently predict negative outcomes in the literature and even appears to be associated with decreased CGB (Hansen & Slagsvold, 2015). Indeed, this research found loss of self was negatively associated with being employed for these 527 spouse and offspring dementia CGs (Skaff & Pearlin, 1992).

Skaff and Pearlin (1992) regressed loss of self, operationalized by Likert responses on questions of feeling loss of a sense of self and of a part of self, on demographic, caregiving, and engulfment variables of number of social contacts and of other roles. Being the spouse of the CR, female, younger, dealing with CR problem behaviors, and level of ADL care were positively associated with loss of self. Contact with friends, but not family, for spouse but not offspring CGs, and working were negatively associated with loss of self (Skaff & Pearlin, 1992). When interaction terms were added, contact with friends was negatively associated with loss of self for unmarried offspring CGs. In support of the benefit of cognitive flexibility, CGs who experienced role engulfment could not see themselves in any other context than caregiver.

Logically, CGs experiencing role engulfment had more depressive symptoms and less mastery

and self-esteem (Skaff & Pearlin, 1992). The researchers did not include length of time

caregiving as they concluded it would not be relevant to loss of self but did not explain why that

would be so. That problem behaviors were the greatest predictor of loss of self, superseding the

authors' construct of role engulfment (Skaff & Pearlin, 1992), suggests the day-to-day vigilance

of caring for a CR with behavior problems may engulf a CG's self in ways that number of

contacts and of other roles does not address.

Simpson and Acton (2013) considered internal discrepancy for dementia CGs related to

emotion work, the effort spent conforming one's emotional expression to norms and expectations

and providing support and validation of another's emotions. They proposed that there are

emotion rules in caregiving and that the particulars of dementia caregiving such as declines in

the CR's capacity to communicate and reciprocate in the relationship, will shape those rules

uniquely. These researchers sought to determine what emotion work dementia CGs do in the

dyadic relationship with the CR (Simpson & Acton, 2013). Content analysis of qualitative data

from previous interviews of racially diverse dementia CGs, seven offspring and four spouses,

and eight women and three men, revealed four categories of emotion work (Simpson & Acton,

2013). *Managing feelings* entailed countering feelings incongruent with being a good caregiver

and adapting to feeling rules that had changed from the precaregiving relationships; *weighing

options* occurred via calculating the best course of action to avoid escalating behaviors or distress

in the CR; *being parental*, similar to role identity, meant reconciling this new aspect of the

relationship with previous role identity; and *ensuring emotional well-being*, as one CG stated,

included always thinking how best to approach the CR (Simpson & Acton, 2013). These CGs

experienced emotional dissonance between what they felt and what they thought they should feel

or allowed themselves to express (Simpson & Acton, 2013). As with role discrepancy, it would be of interest to examine the role of emotional dissonance on caregiving outcomes.

Skaff and Pearlin (1992) sought to better explicate the mechanisms of dementia caregiver distress and it can be said that all the studies in this section provided insight not only into what is distressing about caregiving, but why. Taken in aggregate, these findings support the idea that caregiving is stressful less because of its inherent demands than because of the ways in which its demands challenge CGs' sense of self, beliefs about how they should behave and feel, and their role in relationship to CRs. The current qualitative study can enhance understanding of how dementia CGs experience their sense of self, beliefs, and relationship to the CR.

Making Sense and Finding Meaning

CG beliefs about how they are expected to act and feel are logically associated with the meanings CGs attribute to their situation. Indeed, finding even provisional meaning in the situation itself appears to improve CG outcomes (Farran, Miller, Kaufman, & Davis, 1997). A sociological thesis that people have the capacity to find a sense of coherence (SOC) by meaning-making in the face of complexity and chaos (Antonovsky, 1993a) lends itself well to understanding the process by which dementia CGs negotiate the chaos of ever-changing circumstances.

Finding Meaning

A proposed model of meaning-making in stressful life events distinguished between situational meaning and global meaning and between the meaning-making process and the finding of meaning (Park, 2010). Distress occurred when the appraised meaning of a stressful circumstance was in conflict with existing global meaning. That conflict prompted the individual to search for meaning, the successful end result of which was having made sense, with

resultant changes in global beliefs, goals, and purpose (Park, 2010), fitting with Antonovksy's

(1993b) SOC. This model is reflected in the caregiving literature. For example, finding meaning

but not the search for meaning has been shown to mediate fully the impact of an expressive

writing intervention centered on meaning on the outcome of depression for CGs of persons with

cancer (Fuhrmann, 2015).

Finding meaning did not preclude the burdensomeness of the situation for 84 CGs of a

spouse with mild dementia in a study designed to determine whether finding meaning mediated

the impact of CGB on physical and mental CG health (McLennon et al., 2011). CGB did not

predict physical health, but did predict mental health, and this was partially mediated by finding

meaning in caregiving (McLennon et al., 2011). Strengths in this study were its incorporation of

existential concepts into the dementia caregiving equation, statistical robustness as each step in

the mediation analysis was significant at $p < .001$, and greater ethnic diversity than much of the

caregiving literature. The authors noted the sample was not socioeconomically representative of

the general population of similar aged adults (McLennon et al., 2011).

The measure of finding meaning used in the preceding study, the Finding Meaning

Through Caregiving Scale (FMTC), was designed for use with dementia CGs (Farran et al.,

1999a). Based on themes from qualitative interviews of 94 dementia CGs, the scale incorporated

the participants' words and was subjected to two studies to establish its psychometric properties.

Participants in the first study were mostly White, female, and married with some diversity in

type of relationship to the CR and the second study was all spouse CGs, with more ethnic

diversity (Farran et al., 1999a). The FMTC had good internal validity in both studies for the

overall scale and three subscales, which had good construct validity and performed as expected

in analyses of convergent and divergent validity (Farran et al., 1999a). These subscales are

powerlessness and loss, provisional, i.e. situational, day-to-day meaning, and ultimate meaning.

Concerns were the need for norming on more diverse populations and the primarily religious

nature of the ultimate meaning scale which may preclude its measuring other ways people find

deeper meaning. A study to determine the scale's cross-cultural adaptability found a general fit,

but there were a few items that did not make sense in a Korean culture and a need for new

questions that identify important sources of meaning from a Korean perspective (Lee, Farran,

Tripp-Reimer, & Sadler, 2003). No further work on the psychometric properties of this

instrument was found in the literature.

The paradigm behind the FMTC, based on the existential idea of meaning in

biopsychosocial-spiritual suffering, asserted that Alzheimer's CGs potentially suffer in all four

domains (Farran et al., 1991). Farran et al. (1991) conducted a study of 94 mostly White

dementia CGs of primarily parent and spouse PWDs with responses to open ended questions

regarding how they experienced their lives, including positives and negatives, regrets, hopes, and

needs. Thematic analysis revealed four themes of loss and powerlessness; choice, values, and

meaning, both provisional and ultimate; caregiving resources; and caregiving responsibilities.

While the FMTC questions around ultimate meaning are religiously oriented, approximately

14% of the respondents referred to nonreligious sources of ultimate meaning. Quantitative

analysis of the data revealed little difference in responses by race, gender, or relationship to the

CR (Farran et al., 1991). Apparently because of the authors' existential focus, their intent to

create a measure of meaning, and the latter two themes being more heavily addressed already in

the literature, the researchers did not include them in the discussion or the FMTC (Farran et al.,

1991). Choice of qualitative work to inform development of the FMTC along with participant

quotes as scale items is a strength of this study in conjunction with the preceding one. There is a

conundrum in asserting each CG's experience of suffering and finding meaning is unique while

developing a measure of the experience. The authors noted the themes are neither

comprehensive nor necessarily representative (Farran et al., 1991). The solid theoretical base

and follow-up work noted above, give credence to the results.

Antonovsky's (1993b) SOC and the related idea that people with a strong SOC

experience a healthier life was the theoretical basis for a study that considered satisfaction with

caregiving related to the CR, self, and the dyadic relationship for 153 Swedish dementia CGs

(Andrén & Elmståhl, 2005). The measure of SOC used considered the capacity to make

cognitive sense of one's circumstances, access to necessary resources, and the belief that the

challenge is worthy of the effort (Antonovsky, 1993b). Factor analysis of the satisfaction with

caring measure used identified *purpose*, associated with challenge, growth, and faith, as a

significant factor, thus paralleling both provisional and ultimate meaning discussed above

(Andrén & Elmståhl, 2005). Surprisingly, SOC was not associated with any of the satisfaction

measures; it was significantly related to CG health which fits with the theory and to CGB,

suggesting that the stressors of caregiving challenge CGs capacity to make sense of the

caregiving situation in a coherent way (Andrén & Elmståhl, 2005). SOC, as utilized here,

appears to be both trait and state, with its being deemed enduring and dynamic (Antonovsky,

1993b). It is then logical that the authors proposed straightforward interventions to help CGs

with low SOC cope but emphasized screening to identify those with low SOC whose situations

may not be healthy for either member of the dyad (Andrén & Elmståhl, 2005).

Spirituality

Whether by its promotion of meaning and provision of a SOC in life or some other

mechanism, spirituality, and in particular religiosity, has been studied for its impact on

caregiving outcomes. Utilizing depressive symptoms as the outcome, a study of 200 spouse

dementia CGs, considered whether self-perceived religiosity, private religious involvement via

prayer, and organizational religious involvement via attendance at services moderated or

mediated the effects of objective caregiving stress and related subjective stress operationalized as

role captivity and role overload (Leblanc, Driscoll, & Pearlin, 2004). These participants were

89% White and 82% Christian, primarily Protestant. Religiosity was not associated with

depressive symptoms and had no statistically significant mediation or moderation effect on the

impact of caregiving stressors on depression. Self-perceived religiosity was positively associated

with the subjective experience of stress and role overload, but as this was a cross-sectional study

(Leblanc et al., 2004), there is no indication of directionality. It is possible that those

experiencing greater overload, may lean more on religious beliefs and begin to see themselves as

more religious. The researchers acknowledged that their measures of religiosity may not

sufficiently capture the construct of religiosity in ways that are most meaningful to struggling

CGs (Leblanc et al., 2004).

Using the ultimate meaning subscale of the FMTC, Spanish researchers examined how

religiosity in conjunction with self-efficacy impacted symptoms of depression and anxiety in 122

dementia CGs, 84% of whom were Christian and the remainder nonreligious (Lopez et al.,

2012). Based on measures of beliefs about self and a higher power, these researchers

categorized the CGs as high or low on self-efficacy and spirituality, representing a belief in one's

own capacities and in an empowering Other (high efficacy high spirituality); belief in one's own

capacities without help from Other; doubt in one's own capacities and passive reliance on Other;

and doubt in one's own capacities without help from Other, creating low expectations (Lopez et

al., 2012). Results were greater depression for low efficacy high spirituality than for high

efficacy high spirituality. Including the four conditions and caregiving variables in stepwise

multiple regression analyses, revealed that CG appraisal of CR behaviors predicted anxiety and

depression and high efficacy high spirituality and social support predicted less depression. The

authors theorized that when taken in aggregate, self-efficacy and beliefs in ultimate meaning can

counter feelings of helplessness and hopelessness (Lopez et al., 2012), hallmarks of depression.

  Spirituality, ethnicity, and race. The preceding discussions of meaning-making

identified the relevance of faith, spiritual suffering, and religious and nonreligious ultimate

meaning. The items on the ultimate meaning subscale of the FMTC included references to

God's goodness and sovereignty and the benefits of prayer (Farran et al., 1991). Many of the

CGs in these studies found spirituality to be germane to their caregiving journey. In particular,

Latino and African American CGs have been shown to utilize more religious coping strategies to

deal with dementia caregiving stress than European American CGs. Engagement in prayer and

self-perceived religiosity were correlated with being non-White and being female (Leblanc et al.,

2004; Santos, de Sousa, Ganem, Silva, & Dourado, 2013; Wykle & Segal, 1991).

  Based on the prominence of spirituality in Latino culture, a study of 209 primarily female

Latino American dementia CGs considered whether social support and spirituality, defined as a

search for the transcendent that is particularly salient in stressful situations, was associated with

positive aspects of caregiving (Hodge & Sun, 2012). Controlling for demographic variables

shown relevant to positive aspects of caregiving, structural equation modeling demonstrated that

the CGs experienced significant subjective stress related CR problem behaviors, but not

functional impairment; subjective stress was negatively associated with positive aspects of

caregiving, social support, and spirituality; and spirituality, but not social support, was associated

with positive aspects of caregiving, in a positive direction (Hodge & Sun, 2012). The latter

finding suggests that the benefits of spirituality are independent of the social support that may occur in religious communities (Hodge & Sun, 2012). The authors found nonsignificant evidence that spirituality might partially mediate the effect of subjective stress on positive aspects of caregiving (Hodge & Sun, 2012), but this would require further study. These data were cross-sectional, so no causality can be assumed. It is possible, for instance that CGs able to experience PAC are better able to engage in socially supportive and religious activities. Notably, these CGs were unlikely to be dealing with the stress of recent immigration as the average time in the US was over 30 years (Hodge & Sun, 2012). This study did not address the dichotomy of searching versus finding meaning and it is intuitive that the stresses of caregiving can challenge existing ultimate beliefs. However, these CGs appeared to benefit from culturally embedded existing spiritual beliefs in support of their ability to experience positive aspects of caregiving. Additionally, the authors asserted that spiritual beliefs have the potential to make caregiving itself a sacred activity (Hodge & Sun, 2012).

Because spirituality and religiosity are complex constructs, more specific aspects of spirituality were considered in another study of Latino Americans, specifically 66 mostly coresident Mexican American CGs, 92% of whom identified as Christian, primarily Catholic (Herrera, Lee, Nanyonjo, Laufman, & Torres-Vigil, 2009). Intrinsic religiosity, private and public religious religiosity, and positive and negative religious coping were predictor variables and outcomes variables were CGB, physical and mental well-being, and depression (Herrera et al., 2009). Only 29% of these CRs had dementia by family report, but the presence or absence of dementia was included as a covariate (Herrera et al., 2009). Multiple regression analyses found only negative religious coping predicted outcomes and only for depression in the expected direction; there were no associations of religiosity with physical well-being; intrinsic and

organized religiosity were associated with CGB only; and nonorganized, i.e., private, religiosity

negatively predicted mental health but only at $p < .10$ (Herrera et al., 2009). The lack of benefit

and tentative negative effect of private religiosity that includes prayer, meditation, and Bible

study was surprising. The authors surmised that, unlike the preceding study, the benefits of

organized religiosity might be social and thus the private practice of faith is less beneficial

(Herrera et al., 2009). It may also be that those CGs who engage primarily in private religious

practice may rely more on it because the caregiving situation may preclude more involvement in

the religious community, in which case the negative outcomes would be due to caregiving

stressors. While this study provided some evidence that religiosity plays a role in CG outcomes,

there were few associations. Longitudinal research, as proposed by the authors (Herrera et al.,

2009) and a larger sample size would provide clearer insight into these important constructs.

Like the Latino Americans above, African American CGs, despite fewer material

resources and more objective life stressors including worse physical health (Pinquart &

Sorensen, 2005), experience more positive and fewer negative outcomes (Mbiza, 2015; Pinquart

& Sorensen, 2005; White et al., 2000). Opposite the finding by Herrera et al. (2009),

religiosity's effect on outcomes was not due to attendance at services, but rather comfort from

religion and prayer for a group of nondementia specific CGs (Picot et al., 1997). These aspects

of religiosity partially mediated the increase in rewards of caregiving experienced by African

American as opposed to European American CGs (Picot et al., 1997). Religiosity also mediated

the differential effects by race of caregiving, when the outcome was CGB (Sun et al., 2010).

These rural participants, 67 African American and 74 European American dementia CGs

were higher-hour CGs providing an average of 50 hours a week of care (Sun et al., 2010),

suggesting heavy caregiving loads. CGs completed measures of religious coping related to

dealing with stress, private and organizational religious involvement, and CGB. Statistically

significant racial differences were lower income, greater religious coping and involvement, and

lower CGB for African American CGs, and CGB was statistically negatively associated with

religious coping and organizational religious involvement (Sun et al., 2010). Demographic and

caregiving variables, including dementia severity, found to be associated with both race and

CGB were used as control variables in a mediation analysis, which revealed that organizational

religious involvement was a statistically significant mediator of race and CGB, but intrinsic

religious involvement and religious coping were not (Sun et al., 2010). The authors noted that

religious involvement may be representative of more social support as CGs who attend religious

activities may be more generally social active. The instrument chosen to measure CGB included

items indicating negative feelings toward the CR (Sun et al., 2010), potentially confounding

burden with racial disparities in respect for elders.

Summary of spirituality. Findings regarding caregiving outcomes and religiosity are

diverse in part because of variations in measures used (Lopez et al., 2012). The inconsistencies

related to the role of attendance at religious services and involvement in a religious community

may be in part due to variances in the degree to which communities of faith provide support to

the caregiving dyad. The studies noted above did not account for that possibility. Such

information could add to the knowledge base guiding development of caregiving and societal

systems addressing dementia and caregiving needs to incorporate religious communities as is

being done in Wales (AS Cymru, 2017).

Spirituality broadly defined is less studied than religiosity in caregiving as are non-

Christian faiths, but religiosity appears to improve outcomes for dementia CGs (Herrera et al.,

2009; Hodge & Sun, 2012; Leblanc et al., 2004; Lopez et al., 2012; Picot et al., 1997). Findings

regarding what aspects of religiosity are most beneficial are equivocal and the mechanisms by which it exerts positive influence are unclear. The evidence suggests that European American CGs experience worse mental health and burden outcomes from caregiving than Latino and African American CGs because of a less central role of religiosity in their lives and a greater reliance on problem-solving (Picot et al., 1997). It is not possible to know without further research if religiosity per se or variations in religious coping (Picot et al., 1997) account for these racial disparities or whether, for European Americans, a lifetime of more ready resources creates an arguably false sense of self-reliance and thus less perceived need for religious support, leaving them less prepared for confronting the unfixable of dementia. Support for that notion was the finding that income was negatively associated with depression in European American, but not African American CGs (Pinquart & Sorensen, 2005). It is not reasonable to suggest distressed CGs "get religion" to protect them from caregiving stress. It is of value for those who provide mental health services to dementia CGs to be aware of the coping strengths they possess in their existing religious and spiritual beliefs and of the scant evidence that some aspects of religiosity may be associated with negative outcomes. The interview question about meaning-making and the use of the FMTC scale in the current study provided insight into the spiritual aspects of the participant CGs' experiences.

Predictors and Outcomes

The racial disparity in caregiving outcomes related to meaning are clearly complex. A study of 77 African American and 138 European American coresident spouse dementia CGs considered what impact finding meaning has on caregiving outcomes in relation to other relevant variables (Farran et al., 1997). Demographics considered were age, race, gender and income; caregiving variables were CR care needs, CR behaviors, and CG self-ratings of physical health

and of distress and effort in caregiving tasks; finding meaning was measured by the FMTC

ultimate meaning and provisional meaning subscales; and the outcome variables were measures

of depression and of role strain in caregiving (Farran et al., 1997). The African American CGs

were younger, with lower incomes and more likely Protestant, less distressed by CR behaviors,

scored higher on both measures of meaning, and had less depression and role strain than the

European American CGs. Provisional meaning was associated negatively with both outcome

variables, but ultimate meaning was only correlated with depression also negatively (Farran et

al., 1997). In hierarchical regression analyses, only provisional meaning predicted depression

and role strain and it did so independently of race; the gap between the African American and

European American CGs related to depression widened; and European American CGs

experienced greater distress related to CG behaviors and care needs and more role strain than

their African American counterparts. The interaction terms with race and the meaning measures

were not significant (Farran et al., 1997), leaving the question of what factors support better

outcomes for African American CGs. Other questions raised by this work include why ultimate

meaning had less impact on outcomes than provisional meaning and how the benefits of

provisional meaning could be harnessed to support CGs. The authors suggested a need for

qualitative research to clarify the complexity of findings (Farran et al., 1997).

That finding meaning and searching for it are different constructs (Park, 2010) with

different caregiving outcomes (Fuhrmann, 2015) has been discussed above. Finding meaning

was the outcome variable in a study of 447 dementia CGs, mostly White, female, and spouses of

the CR, referred by the Admiral Nurse Service in the UK (Quinn, Clare, & Woods, 2012).

Predictor variables were intrinsic and extrinsic motivation to provide care, self-rated religiosity,

preexisting and current dyadic relationship quality, role captivity, and self-rated competence in

caregiving. Meaning was measured by a 12-item Likert scale of meaningful and positive aspects of caregiving. Meaning was significantly related to all predictor variables and, in a hierarchical regression analysis, role captivity predicted lower meaning and intrinsic motivation, competence and religiosity predicted higher meaning, explaining 39% of the variance in meaning (Quinn, Clare, & Woods, 2012). Similar to high efficacy high spirituality group in the work by Lopez et al. (2012), those CGs who had greater religiosity and greater sense of competence, were more likely to find meaning (Quinn, Clare, & Woods, 2012). The study had a low response rate and lacked ethnic diversity. Longitudinal work would be useful to better understand the interplay of the many factors that predict outcomes for dementia CGs and the role of meaning.

Qualitative Work on Meaning in Dementia Caregiving

The preceding discussion of the importance of provisional or day-to-day meaning for dementia CGs relates to the qualitative findings by Välimäki et al. (2012) regarding how dementia caregiving families restructure their lives. This study, informed by Antonovsky's (1993b) SOC, was based on the diaries of 83 Finnish dementia CGs written in the first six months after diagnosis, and focused on the question, "What is your life like now that a member of your family has Alzheimer's disease?" (Välimäki et al., 2012, p. 482). The primary themes were the meaning of disease onset for the family and "restructuring life in its entirety" (Välimäki et al., 2012, p. 483). Under the latter theme were subthemes of living in a tunnel, with a variety of emotions shared and descriptions of role captivity; of finding harmony related to spirituality, love for the CR, and altruism; and of the future, some with confidence they could create a new future and others with hopelessness (Välimäki et al., 2012). It is important to recognize that these CGs were early in the caregiving journey, yet they evidenced significant strides in making sense and finding meaning in their situations. It is logical to think the progress would continue,

but it cannot be assumed that all CGs are able to find meaning. This glimpse into the early

months of dementia caregiving can inform mental health services for CGs and suggests an

existential perspective might be beneficial. An additional subtheme of family cohesion,

including challenges to cohesion, also echoes the relevance of family systems. This study had

the strength of data from a large number of participants, although the 63% (Välimäki et al.,

2012) of those who agreed to complete a diary and did so may have differed in an important way

from those who did not. For instance, those struggling more with accepting the diagnosis or

dealing with behavior problems and unable to make sense or find meaning, may have chosen not

to complete their diaries.

Because the role of religiosity in finding meaning in caregiving is not straightforward, it

is valuable to use qualitative methods to deepen understanding of the concept. Unintentionally,

that occurred as spirituality spontaneously arose in a study of 45 dementia CGs of CRs in all

stages of Alzheimer's disease who participated via exploratory structured interviews that were

not guided by prior literature review (Smith & Harkness, 2002). When the significance of

meaning-making became clear in the first interview, a meaning-making question, "'If you were

to ask your mother how she would want to be remembered, what do you think her response

would be?" was added (Smith & Harkness, 2002). Using a broad concept of spirituality as being

religious or secular, i.e., nondeistic, the researchers identified references to spirituality in 80% of

the transcripts and most were religious and positive in nature (Smith & Harkness, 2002).

However, one third of the those who referenced spirituality spoke negatively of their experience

with church communities, but even among those there were descriptions of spiritual growth in

the caregiving journey. Many CGs also spoke of the caregiving experience having a purpose and

changing them (Smith & Harkness, 2002). These authors promoted a multidimensional systemic

approach that sees the individual as a biopsychosocial-spiritual system mutually impacting other members of the family system (Smith & Harkness, 2002), They emphasized that these findings suggest spirituality is integral to the caregiving experience and thus mental health providers need to incorporate spiritual awareness into practice with CGs. Member checking and a third party who audited for consistency and bias ensured reliability of the data (Smith & Harkness, 2002).

Summary of Making Sense and Finding Meaning

Meaning-making does not entail creating a pseudo meaning akin to Marx's (1970) "opium of the people" (p. 131), but rather striving to take that which is discordant and bring it into harmony. It is likely that both discovery and creation are engaged in to find meaning and thereby achieve Antonovsky's (1993b) SOC, which can influence CG outcomes (Andrén & Elmståhl, 2005; Välimäki et al., 2012). The findings in this literature review are helpful in better understanding the experience of dementia caregiving, but their multiplicity reiterates its idiosyncrasy. The role of spirituality in caregiving coping is complex and it is important to avoid painting all members of an ethnic group with the same brush, but the evidence suggests that the differences in how Latino American, African American, and European American CGs experience the phenomenon is in part related to ultimate meaning. A deeper understanding of these dementia caregiving experiences can shed light on how CGs make sense of and find meaning in their journeys.

The Mental Health Needs of Offspring Dementia Caregivers

Preceding discussions have presented evidence that the dementia caregiving journey provides opportunities and yet is fraught with stress. What remains to be elucidated is the way that those who embark on a journey of parent dementia care experience it.

Dementia care of a parent appears to differ from that of a parent without dementia as

evidenced by a study of mostly female, White, non-coresident offspring CGs, 195 whose parent

did not and 110 whose parent did have a diagnosis of dementia (Carruth, 1996). Surmising that

PWDs would be less able to reciprocate in a relationship with their CGs, the author hypothesized

that the quality of CG perceived reciprocity would be associated with a diagnosis of dementia,

along with demographic variables, motivations for caregiving, and interactive patterns and that

dementia and nondementia offspring CGs would differ on the predictor variables other than

demographics (Carruth, 1996). The measure of reciprocity, designed to enumerate balance in

relationships, had four subscales: warmth and regard, intrinsic rewards of giving, dyadic love and

affection, and balance within the family system related to caregiving (Carruth, 1996). The

measure of motivation to care was primarily based on factor analysis which identified

motivations of obligation or of loyalty, commitment, and an added item, intuitively derived, of

keeping the loved one out of a nursing home (Carruth, 1996). Interactive patterns around caring

were assessed for positive or negative exchanges around five types of caregiving activities

(Carruth, 1996). Controlling for demographics, the dementia CGs provided more care, had less

positive interaction with the CR, and less reciprocity on all subscales except love and affection;

although in multiple regression analyses, after controlling for all other variables, the dementia

diagnosis did not contribute to variance in any of the reciprocity subscales (Carruth, 1996). That

satisfactory balance related to reciprocal love and affection with the CR is not statistically

different between nondementia and dementia offspring CGs (Carruth, 1996) suggests that the

latter were still able to experience their parents' love. How they continue to experience a

dementia parent's love would be an important phenomenon to explore via qualitative research.

This study did not assess level of dementia severity or behavior problems, which studies have

shown to negatively impact CG outcomes (Pinquart & Sorensen, 2003; van der Lee et al., 2014;

Wolfs et al., 2012) so it is possible that those who chose to participate may have been caring for a parent whose symptoms were not yet highly troublesome such that their experiences did not differ highly from the nondementia CGs.

The Differential Experience of Offspring Caregivers

The preceding research provided some evidence that for offspring CGs, whether the CR has dementia shapes the caregiving experience. A related question for dementia CGs, is how being an offspring versus other relation, most typically spouse in the literature, shapes the caregiving experience. That question is addressed here.

A study of the moderating effect of CG-CR relationship on the impact of CR behavior problems on CGB for nearly 1,000 caregiving dyads was part of a national survey in Taiwan (Lin & Wu, 2016). These CGs were grouped by relationship with the CR, with percent of the sample provided, as wife (26%), husband (9%), daughter-in-law (28%), daughter (10%), son (18%), and other (9%). There were no interaction effects of relationship x behavior problems on emotional or time burden but, when dealing with a CR's behavior problems, being a wife was associated with more relational burden; being a daughter-in-law was associated with higher financial burden; and being a daughter versus a son was associated with greater total CGB (Lin & Wu, 2016). Societal expectations of offspring to care for a parent are stronger in Taiwan than in most western countries and are more likely to extend to daughters-in-law (Lin & Wu, 2016); and these CGs were less predominantly female, less educated, and more likely to be coresident with the CR than in most U.S. studies, limiting generalizability to the US. However, the sample size supports generalizability, though primarily to the Taiwanese population samples. The authors' suggestion that awareness of relationally based differences in experiencing the burdens of dementia caregiving should guide interventions to support CGs (Lin & Wu, 2016) is apropos.

Relevant to the current study, Lin and Wu (2016) found significant differences in offspring

dementia CGs' experience of CGB by gender and only weak spouse versus offspring differences.

A study of a group of Australian CGs compared 43 spouse versus 47 offspring CGs

directly and, while including CGB as an outcome, added a meaningful variable related to CG

mental health that considered depression, anxiety, and stress (Kaizik et al., 2017). The CRs in

this study were diagnosed with frontotemporal dementia, a disorder characterized by less

memory loss than in Alzheimer's disease, that entails variants that have primarily

communicative or behavioral deficits. In independent t tests, the spouse and offspring CGs did

not differ with regard CGB, depression, anxiety, or stress. Offspring CGs did have a worse

relationship with the CR and smaller social networks than the spouse CGs (Kaizik et al., 2017).

Stepwise regression analyses used CGB as the outcome variable and the mental health factors as

predictor variables with differential result by relationship. Seventy percent of spouse CGB was

predicted by severity of dementia and 7% by depression, but for offspring CGs the only predictor

of CGB was depression which predicted 51% (Kaizik et al., 2017). Because of the unique

challenges of frontotemporal dementia, the younger age of these participants, with offspring CGs

averaging in their early 30's, and the fact many offspring were not the primary CG (Kaizik et al.,

2017), findings may not be readily generalized. While the cross-sectional nature of this study

precludes conclusions about causation such that offspring CGs may have been more depressed

because of the CGB, this study emphasized the importance of addressing depression for

offspring dementia CGs.

Predictive Factors of Offspring Dementia Caregiver Mental Health

There appear to be differences in outcomes for dementia CGs who are offspring versus

other relations, but little is known about what predicts positive or negative mental health for

these CGs. A study that directly addressed emotional and psychological distress, measured by

the Global Severity Index of the Brief Symptom Inventory, specifically considered only sons and

sought to determine the influence of the bond with the CR on CG distress (Daire, 2004). For

offspring CGs, the bond with the CR is a logical outgrowth of the developmental parent-child

bond and thus this researcher used a retrospective measure of the CG's perception of the

relationship with the parent in the first 16 years of the CG's life, the Parental Bonding Instrument

(PBI; Daire, 2004). For these 40 White, mostly married sons the PBI subscale of *care*, but not

that of *overprotection* or the interaction of the subscales, had a significant main effect attributed

to caregiving, with greater *care* associated with less attributional distress (Daire, 2004). In

follow-up analyses, only *care* was associated with a second outcome variable of self-rated

percentage of emotional distress attributed to caregiving, with greater *care* associated with less

attributional distress and there was no association of predictor variables or the interaction with

Global Severity Index (Daire, 2004). That the CRs in this study lived in assisted living facilities

likely means that the stresses experienced by these CGs differed from those caring for a parent in

the community, but the researcher chose this option to control for extraneous variables of

differences in the caregiving situation (Daire, 2004). The author suggested clinical use of the

PBI for deepening understanding of the caregiving milieu for clinician and CG alike (Daire,

2004).

       The role of interpersonal support and stress. A two-year longitudinal study begun

immediately after the CRs' diagnosis of dementia of 57 daughter CGs and their social networks

considered the role of emotional and practical support and interpersonal stress emanating from

those networks with focus on friends and siblings (Suitor & Pillemer, 2007). *Network* was

operationalized as the persons named by the CGs as a practical or emotional support or as a

source of criticism or making caregiving harder. At the beginning of the study and two years

later, siblings were the greatest source of interpersonal stress and of practical support, and friends

were the greatest source of emotional support with little change in the degree of stress and

support over time (Suitor & Pillemer, 2007). Accompanying qualitative data reflected strong

negative feelings toward siblings who were sources of stress based on expectations that siblings

should be supportive and breakdowns in relationships around not receiving expected support,

including in sibling relationships that had been close. These were all married women, but the

support from husbands was little mentioned (Suitor & Pillemer, 2007), suggesting an additional

important line of inquiry into offspring dementia CG social supports.

Family conflict regarding diagnosis of the CR and its implications, treatment of the CG,

and interactions with the CR were explored related to depressive symptoms in spouse and

offspring dementia CGs (Semple, 1991). The only dimension of conflict predictive of

depression was treatment of the CG, which the researcher suggested may trigger invalidation and

self-doubt, increasing the chances of depression. For both spouse and offspring CGs conflict

around the treatment of the CR was associated with the sibling group that composed the

offspring CGs' siblings and the spouse CGs' children (Semple, 1991). The author suggested

that, while this study focused on conflict related to caregiving in the present, there may be

important factors of family conflict from the past relevant to caregiving outcomes (Semple,

1991). This study provides further evidence that sibling relationships in offspring dementia

caregiving have the potential to be a source of interpersonal stress.

A Unique Experience

The preceding discussions have demonstrated that offspring CGs have different mental

health needs, predictors of outcomes, and supports in dementia caregiving than spouse and other

CGs and their journey may be fraught with sibling conflict and shaped by a developmentally

significant relationship with the CR. The differences are complex and in need of clarification.

Harper and Lund (1990) set out to establish a model of CGB via an exploratory study that

considered the relationship of CG to CR, CG gender, and place of CR residence. Demographic

and situational variables, measures of satisfaction with life, CGB, and social support, and CR

need for care, cognitive status and behavior problems were the predictor variables. The 409 CGs

in the study did not include sons as there were only 20 in the original sample, creating groups too

small for statistical analyses. Thus, the CGs under consideration were wife, husband, and

daughter CGs and these were grouped as coresident, having the CR in residential care, or having

CR living in the community separate from the CG, which included only daughters (Harper &

Lund, 1990). Coresident daughters had the highest CGB and those living separately from their

parent in the community had the lowest. Regression analyses were done for each of these seven

conditions. For the purpose of the current study, two are addressed here. For coresident

daughters, 46% of variance in CGB was explained by life satisfaction, rapid decline in the CR,

caring for a father rather than a mother, and an interaction term of working part-time and having

others, not including the CG and CR, living in the home (Harper & Lund, 1990). For daughters

whose parent lived separately from them in the community 54% of the variance in CGB was

explained by CR symptoms, life satisfaction, CG health, and interaction terms of life satisfaction

with CR symptoms (Harper & Lund, 1990). These data suggest that caregiving is experienced

very differently for daughters based on whether they are living with the parent and, in

comparison to the remaining analyses in the article, for daughters as compared to spouse

dementia CGs. This study makes a strong case for both recognizing the heterogeneity of

dementia CGs and giving attention to their individual experiences.

The importance of attending to individual CG experiences was further supported by a one-year longitudinal study comparing CGB in spouse and offspring CGs in Canada of whom 70% were spouses, 69% female, and 96% White (Chappell, Dujela, & Smith, 2014). Predictor variables were demographics; PWD factors such as function and behavior; hours spent and length of time caregiving; external and internal sources of support such as social and formal support, and physical and psychological well-being; the closeness of the precaregiving dyadic relationship; the experience of positives in caregiving; and spirituality (Chappell et al., 2014). Data were gathered at the beginning of the study and at one year and demonstrated greater burden in the offspring CGs than the spouse at both points, though there was a significant decline across time for offspring, while spouse CGB did not change. The multiple regression analyses revealed that spouse and offspring CGs differed more on predictors of stress at the beginning of the study than at year one and that the burden for both was predicted by changing demands of caregiving and by their own anxiety at year one but not at the beginning of the study (Chappell et al., 2014). No variables measured at the beginning of the study other than CGB predicted year one CGB, which the authors asserted supports the relevance of focusing interventions on immediate CG stressors (Chappell et al., 2014), not unlike the suggestion by Montgomery & Kosloski (2009) that services be timed to occur when CG needs are most salient. Feeling lonely significantly contributed to burden at both times for both sets of CGs (Chappell et al., 2014). This study with its large number of participants, longitudinal nature, and depth of variables considered, provides strong evidence of the differential nature of the caregiving between spouses and offspring and the importance of individualized approaches.

Qualitative Work on Offspring Caregiver Mental Health

Qualitative work provides such an emphasis on individuality of experiences. While there

is little qualitative work specific to the mental health of offspring dementia CGs, two studies do offer light on the phenomenon of siblings negotiating parent care, which as noted, appears to be a potential source of interpersonal stress for the CGs of interest.

Acknowledging that gender roles are a product of the societal system, Matthews (1995) assumed that they are also negotiated through interaction in families and sought to better understand that phenomenon via qualitative analysis of data from 50 White brother-sister dyads whose parent lived in the community and in which there was no other sister. Participants completed questionnaires and interviews with open-ended questions that included how siblings negotiated care and the siblings were interviewed separately to reduce bias (Matthews, 1995). These data were coded with attention to gender references, resulting in themes of acceptance of the cultural gender norm in caregiving, sisters being in charge, and brothers' assistance being deemed inconsequential by both sisters and brothers even when clearly not accurate, the latter two reflecting beliefs that females are the experts on caregiving and family matters (Matthews, 1995). Conflict occurred around standards of care and sisters' dissatisfaction with their brothers' contributions (Matthews, 1995). Because gender roles are culturally embedded, it is important to realize that these CGs were all European Americans. While it is hoped that the gendered nature of caregiving may have changed in the over 20 years since this article was published, in 2015 60% of all CGs, including those caring for children, were female (AARP-PPI & NAC, 2015b) and that percentage held steady for CGs providing care to someone over 50 (AARP-PPI & NAC, 2015a). For dementia CGs, 62% are female (National Poll on Healthy Aging & University of Michigan, 2017), and 38% are specifically daughters of the PWD who spent more time in caregiving then did son dementia CGs (Friedman, Shih, Langa, & Hurd, 2015). Thus, it seems likely that dementia caregiving to a parent continues to be strongly gendered.

Beyond sibling gender, the negotiation of caregiving in a family may reflect the dynamics that preexisted transitions to caregiving, which, along with the role of socioeconomic status, was the focus of a mixed methods study of 40 offspring CGs, of whom only a third received help from siblings (Merrill, 1996). These participants were White, just over half working class and the remainder middle class, and 70% daughters, 18% sons, and 12% daughters-in-law. Being male, perhaps because of sons reporting they demanded assistance and daughters reported asking, and being from a working class were both associated with increased likelihood of having a sibling network of support; yet for the latter there was nearly twice the rate of conflict than in middle class families. Content analysis revealed conflict around wanting more help from siblings, especially for coresident CGs (Merrill, 1996). The CGs sometimes attributed conflict to the caregiving situation itself, with some verbalization of surprise their siblings were not more cooperative, and others attributed it to longstanding family issues both from childhood and from events in adulthood. Conflict was a prevalent theme, but because the interviews sought information about sibling conflict (Merrill, 1996), it cannot be ruled out that the results were biased. Differently worded but similar questions that resulted in consistent answers for most respondents provided validation of data (Merrill, 1996). The significance of family conflict and of more than just caregiving stressors contributing to the conflict provided insight in the ways that mental health treatment can help offspring CGs and the importance of considering the family system.

Mental Health Treatment

That caregiving can be highly stressful with negative emotional and psychological outcomes has been demonstrated and the differential experience of being female, an offspring, and caring for a PWD has been discussed. It seems clear that offspring dementia CGs have

noteworthy mental health needs and it is therefore incumbent to explore appropriate treatments.

From a collaborative perspective it is imperative to consider what a client receiving mental

health services desires, which may be even more important for those immersed in caregiving

with limited time and resources. A Swedish study found for CGs experiencing both high and

low impacts of caregiving, information about dementia, previously discussed as a need of CGs

(Cascioli et al., 2008) that is sometimes poorly met (Drennan et al., 2011), resulting in increased

stress for CGs (Feinberg & Levine, 2015; Stirling et al., 2010) and counseling, operationalized as

having someone to talk to, were the most important desired services, although help in dealing

with family conflict was not desired (Alwin et al., 2010). Because mental health counseling is

not provision of just a listening ear, these findings suggest consideration of nonprofessional

support might be sufficient. However, when an RCT of such a befriending program was

conducted in England, there was no significant effect versus controls on CG depression or health

related quality of life (Charlesworth et al., 2008). The question remains whether offspring

dementia CGs might benefit from treatment of their mental health needs.

A quasi-experimental study in Sweden of 153 dementia CGs in the treatment group and

155 in the control group did not specifically target offspring CGs, but it did provide differential

data on their responses to treatment (Andrén & Elmståhl, 2008b, 2008c). The outcomes for this

research were benefits to both members of the dyad, time to nursing home placement for the CR

(Andrén & Elmståhl, 2008b), and, at six months and 12 months, CGB and CG satisfaction

(Andrén & Elmståhl, 2008c). The intervention entailed ongoing available telephone support and

group psychoeducation followed by emotion-focused strengths-based support/conversation

groups that were professionally led (Andrén & Elmståhl, 2008b, 2008c) and could consequently

be deemed pseudo-psychotherapy. The intervention was statistically significantly related to

longer time to nursing home placement when CGs were offspring, but not for spouses or other

relations and, when the CG was a daughter as opposed to a son, time to placement was longer

(Andrén & Elmståhl, 2008b). For the intervention group, at six months, levels of strain and

disappointment were significantly lower, and satisfaction was significantly higher than the

control group and at 12 months, for spouses only, strain remained significantly lower than for

controls (Andrén & Elmståhl, 2008c). This study's long timeline and multiple follow-up

measures and its consideration of outcomes for CR and CG and indirectly for the societal system

due to the impact of nursing home placement, make its findings unique. The treatment offered

was not truly psychotherapy yet appeared to offer benefits of knowledge and support that were

particularly helpful for spouse CGs related to caregiving stress and for daughters related to

nursing home placement. This study not only demonstrated that interventions can be effective

for dementia CGs, but that offspring CGs, particularly daughters, experience the benefits

differently, suggesting that mental health needs may differ by relationship to the CR.

Resources for enhancing Alzheimer's caregiver health. The Resources for

Enhancing Alzheimer's Caregiver Health (REACH), funded through agencies of the National

Institutes of Health, was a multisite RCT of interventions for 1,222 diverse U.S. dementia CGs,

with high CGB and depressive symptoms at baseline, caring for CRs whose dementia was

moderate to severe at baseline (Wisniewski et al., 2003). The nine interventions that include

education, technological support, training in dementia care, and peer support groups (Wisniewski

et al., 2003) are beyond the scope of the present literature review and only those that are

primarily mental health counseling are addressed here. This powerful research project developed

common outcome measures to allow for analysis across sites and interventions and produced

large amounts of pooled data (Wisniewski et al., 2003). Some of its findings have been

expanded internationally (Cheung et al., 2015) and have been used to develop an evidence-based action guide to support those who provide services to dementia CGs (University of Michigan's Institute of Gerontology & The National Association of Chronic Disease Directors, 2009). The latter was developed from the second project, entitled REACH II, an RCT of a multicomponent intervention based on the outcomes from REACH that was implemented in multiple sites and with racially and ethnically diverse participants (Elliott et al., 2010). This was primarily a training intervention (Elliott et al., 2010) and will not be discussed here.

The Memphis site for REACH conducted a two-year study in a primary care setting that compared two versions of a pamphlet-guided, primarily educational intervention conducted by a master's level *educator-interventionist*, behavior care that taught management of CR behaviors, and enhanced care that added cognitive behavioral therapy principles to teach coping skills for the CG (Burns et al., 2003). The study is of interest here because of its use of CRs' primary care location in keeping with previous discussions of the importance of PCPs in supporting CGs and their potential as a one-stop shop for information, its use of psychotherapeutic principles if not actually therapy, and its comparison of treatment with and without those principles (Burns et al., 2003). CGs were 60% European American, 39% African American, and the remaining *other*; approximately half were spouses, which is logical given that only coresident CGs were included; mostly women; and on average caring for a CR with severe dementia. Outcome variables, measured every six months for two years starting at baseline, were of CG general well-being, depression, and bother due to CR behaviors. Only general well-being was significantly different between groups, with those in Enhanced Care reporting better well-being across the two years (Burns et al., 2003). Findings are tentative as there was no control group, and because interventionists spent a third more time with CGs in the Enhanced Care intervention (Burns et

al., 2003), differences in outcomes may have been due to dose effect. Most significantly, intervention times were much shorter than designed, indicated low fidelity, poor engagement by CGs, or both, and thus there was little in the intervention other than content that reflects psychotherapy.

The Miami site of REACH utilized a control condition of minimal contact to compare outcomes of a brief family systems intervention and the intervention plus a computer-telephone integrated system to support CGs in accessing services and receiving the therapy from home if needed (Eisdorfer et al., 2003). The therapy, structural ecosystems therapy, supports CGs in identifying and ameliorating problems in the family system and other relevant systems and was designed to provide up to 45 hours of therapy over 12 months and to be delivered primarily in the CGs' homes (Eisdorfer et al., 2003). Participants were nearly half Hispanic and half non-Hispanic European American, 75% female, and nearly two-thirds spouses, again related to the requirement that the dyads be coresident. Outcome variables were depression, bother due to CR behaviors, and satisfaction with social support, measured every six months from baseline to 18 months with the following significant results for depression (Eisdorfer et al., 2003). CGs in therapy only had higher scores than those in therapy plus the computer-telephone intervention at six months, and at 18 months, all CGs in therapy plus the computer-telephone intervention had lower scores, European American CGs in the therapy only condition had higher scores, and Hispanic CGs in the therapy only condition had lower scores (Eisdorfer et al., 2003). Those in the therapy plus the computer-telephone intervention condition had approximately 36% (14 hours versus 19 hours) more contact time than those in therapy only and nearly 4.5 times the number of contacts (13 versus 56; Eisdorfer et al., 2003). Thus, there were many more brief contacts, suggesting more doses of lower potency, confounding the results. These findings

suggest that the family therapy portion of the intervention was not beneficial related to CG depression, except at 18 months for the Hispanic CGs, and potentially worsened depression for European American CGs (Eisdorfer et al., 2003). Conclusions are difficult but there is a clear need for understanding what does work to improve mental health for specific CGs such as offspring dementia CGs.

The New York University Caregiver Intervention. That CGs are often referred to in the literature as *family caregivers* speaks to the imprudence of ignoring the family system in CG interventions. Family therapy was integral to the preceding intervention, although its benefits are dubious, and is also a core component of the NYUCI (Mittelman et al., 2003). This intervention was designed for and researched with spouse dementia CGs and incorporates individual counseling, family counseling, support groups, and telephone ad hoc counseling (Mittelman, 2003). Its purpose was to decrease negative outcomes for CGs and increase the time that CRs can remain at home (Mittelman, 2003). It does so by improving CG understanding of CR behaviors and altering appraisals of them, decreasing family conflict, and increasing positive support from family and, via the support group, from other CGs. The intervention is designed to be readily individualized, in recognition of the idiosyncrasy of the caregiving experience; to provide problem-solving and referrals as needed, meeting the call for information; to have ready availability via telephone, as was the beneficial portion of the above study (Eisdorfer et al., 2003); and to decrease isolation and provide safety and connection in support groups. The family counseling portion is meant to improve communication and family members' knowledge about dementia and the specific caregiving situation, and also to decrease conflict and increase cooperation and support (Mittelman, 2003). The NYUCI is particularly well studied with consistently positive results for spouse CGs (Mittelman, 2003; Mittelman et al., 2003).

This successful intervention was extended to offspring CGs of a parent living in the

community in an RCT with 54 CGs in the treatment group and 53 in a control group over three-

year follow-up (Gaugler et al., 2015). The NYUCI protocol of one individual, four family, and a

final individual session was altered for the offspring CGs who resisted the family sessions, but

otherwise fidelity to protocols was closely monitored (Gaugler et al., 2015). Outcome variables

were CG role captivity, emotional and physical fatigue, appraisal of CR problem behavior

(Gaugler et al., 2016), quality of life and depression (Gaugler et al., 2015), and time to nursing

placement of CR (Gaugler et al., 2013). Compared to controls, CGs in the treatment condition

had decreases in negative reactions to CR behaviors (Gaugler et al., 2016); improvements in

quality of life and depressive symptoms of isolation, apathy, and withdrawal (Gaugler et al.,

2015); and were less likely to admit the PWD to residential care and doing so took 228 days

longer (Gaugler et al., 2013). The ability to react less negatively to CR behaviors is beneficial to

both members of the dyad and may partially explain the ability to continue caregiving in the

community longer, which in turn is beneficial to an overtaxed caregiving system and places less

financial burden on the societal system. These outcomes occurred despite some of the control

group participants engaging in counseling on their own (Gaugler et al., 2013).

These CGs were almost exclusively European American females, limiting

generalizability. That this is an effective treatment for daughter dementia CGs is strongly

supported, although it is effectively quite different from the intervention with spouse CGs for

whom individual to family counseling occurred at ratio of 2:4 (Gaugler et al., 2015). For the

offspring CGs the ratio was 4:1, averaging just over one family session instead of the original

four for each CG (Gaugler et al., 2015). Considering the significance of the family system

related to dementia caregiving these results leave a question of how or even if to address FoO

issues related to offspring caregiving. While the authors offered no explanation other than

participant choice, the use of the term *very resistant* is telling, particularly considering that CGs

gave informed consent (Gaugler et al., 2015). It seems likely that there may have been some sort

of discord whether overt or covert and perhaps offspring CGs carry that load in addition to the

caregiving burdens.

Summary of Mental Health Needs of Offspring Dementia Caregivers

Throughout the discussion of offspring CG mental health and indeed the larger

discussion, it is evident that dementia caregiving is an idiosyncratic experience with some

commonalities that are differential by race and ethnicity, gender, coresidence with the PWD, and

relationship to the CR. One group of CGs that stands out related to impacts of caregiving is

coresident adult daughter CGs (Harper & Lund, 1990), the participants for the current study.

Conflict in the family system appears to center largely around sibling relationships and to

emanate from stressors from caregiving itself and those that predated caregiving from both

childhood and adulthood. The evidence is not clear if this has a clinically significant impact on

CGs' experience of caregiving or serves more as a source of annoyance and frustration compared

to the daily burdens of care. However, while the data are equivocal or lacking related to clinical

significance, researchers reflected CGs had strong negative feelings around sibling conflict

(Suitor & Pillemer, 2007) and were highly resistant to engaging in family therapy (Gaugler et al.,

2015), suggesting that these are not minor annoyances. Additionally, having grown up in a

family system that they recalled as caring was associated with less CG distress (Daire, 2004).

The preceding principles can guide offspring CG interventions, of which there are few

that are specifically psychotherapy, and the NYUCI incorporated many of them with evidence of

being an effective treatment for these CGs. Complicating implementation of effective treatments

is the differential effects related to race and ethnicity and to relationship with the CR. From the needs and experiences identified in the literature it would seem that family therapy should be incorporated, but the results of treatments designed to do so were either not helpful to or not wanted by offspring CGs, leaving uncertainty as to how to help them address family conflict and benefit from family support. Because of the evidence that mental health counseling can increase time to placement of the PWD in residential care, the societal system would be wise to invest in development of further treatments, clarification of differential benefits of specific therapies, and expansion of evidence-based interventions. It is clear that compared to other CGs, offspring who care for a parent with dementia experience its stresses and outcomes differently.

The Contributions of Interpretative Phenomenological Analysis to This Topic

The current study aimed to bring to light the lived experience of coresident offspring dementia CGs via IPA relative to mental health in relational and systemic contexts with consideration of how they construct meaning and address challenges to identity. Thus, it is important to explore the contributions already made to the topic via this means of inquiry, which is effective in increasing understanding of how people experience threats to identity related to meaning-making, cultural values, and self-esteem (Timotdevic & Breakwell, 2000); intentionally idiographic (Galvin et al., 2016; Montgomery & Kosloski, 2009), thus fitting well with caregiving as an idiosyncratic experience; well suited to existentially meaningful constructs (Smith & Shinebourne, 2012) such a caring for a loved one who is losing essential capacities; and centrally focused on meaning-making (Smith et al., 2009).

Preceding discussions of the challenge to CGs of adapting to the changing dyadic relationship and the importance of the quality of that relationship to caregiving outcomes were reflected in the themes identified from an IPA of interviews of 12 dementia CGs (Quinn, Clare,

& Woods, 2015). This study sought to deepen understanding of how the lived experience of caregiving is influenced by meaning, motivation and relationship dynamics via analyzing data from semi-structured interviews of four female offspring, six wife, and two husband CGs recruited by the Admiral Nurse service in England (Quinn et al., 2015). IPA thematic analysis, first of individual interviews and then across all interviews, identified six subthemes using the participants own words, entailing loss, "the person is different" (p. 225); relational changes, "I do miss the companionship" (p. 226); a heavier load, "I miss the help" (p. 227); having no option but to provide care; "you just get on with it" (p. 229); preserving the dignity of the PWD; "just trying to find a balance" (p. 228) between protecting the CRs and promoting their quality of life; and a "turning point" (Quinn et al., 2015, p. 230). Turning points occurred when the overarching theme of balancing needs, became too lopsided for the CGs to continue (Quinn et al., 2015). While not considered a theme, the dyadic relationship was identified as significant motivation for caregiving and a source of meaning and of positives and negatives (Quinn et al., 2015). Strengths of this study included use of decontextualization to ensure the data were true to the original transcripts and the use of multiple analysts who achieved consensus on the themes (Quinn et al., 2015).

Even in early stage dementia caregiving, changes in the dyadic relationship were identified as a theme, when data from semi-structured interviews of 34 spouse or partner CGs recruited from memory clinics in England was conducted via IPA (Quinn, Clare, Pearce, & Van Dijkhuizen, 2008). Additional themes were the challenges of understanding and dealing with the diagnosis, other difficulties in caregiving, and learning to cope. The purpose of this exploratory study was to better understand the internal experiences of these CGs as they negotiated the changes of this early period (Quinn et al., 2008). These CGs appeared to be in the very

beginning of the dementia caregiving journey and so the data should best be thought of as descriptive of the inner experience of a highly stressful, transitional time of uncertainty. The interviewers did not use terms such as dementia, Alzheimer's, or caregiving unless the interviewee first did because they were unsure what had yet been told to them by the memory clinic. This hesitance to verbalize the realities of the situation suggests that perhaps the theme of not knowing may have been the result of being so early in the experience (Quinn et al., 2008). The previously discussed work by Välimäki et al. (2012) provides a picture of dementia CGs a few months into the experience after the diagnosis had been clearly explained to them. The themes found by Quinn et al. (2008) were checked with the original transcripts to ensure fit with the data and the researchers used multiple analysts.

The preceding two studies were conducted in England with solely White CGs. It is important to consider caregiving, a culturally embedded concept (Santos et al., 2013), from diverse perspectives. IPA, best conducted on homogenous samples (Smith et al., 2009), was conducted with two Hispanic female CGs, a daughter and a granddaughter in the US, based on semi-structured interviews around caregiving mastery, additional open-ended questions, and researcher field notes (Simpson, 2010). The theme of reconciling self in the caregiving role again reflects the idea of caregiver identify theory as these CGs struggled with things such as taking a parental role with their mother or grandmother (Simpson, 2010). Other commonalties were experiencing caregiving positively, influenced by cultural values and a sense of mastery that was only lessened when they experienced role discrepancy related to their sense of self as caregiver. The researcher sought to check her themes with expert qualitative consultants to ensure accuracy (Simpson, 2010).

The capacity to experience caregiving positively was also identified in an IPA

investigation of 18 primarily female spouse and offspring coresident dementia CGs of CRs with

mild dementia participating in an interactive, supportive psychoeducation group in Brazil (Santos

et al., 2013). Three themes, reasons for becoming a CG, awareness of dementia symptoms, and

awareness of the identity of the PWD, were identified from the data. Naturally arising from

culturally embedded familism, *responsibility* fit many of these CGs reasons for caregiving better

than *obligation*. Awareness of dementia symptoms varied, but for some CGs, being unaware

played a role in preserving the dignity of the CR, fitting with the final theme focused on the

identity of the CR (Santos et al., 2013). The authors also noted many CGs experienced

ambivalence and appeared not to make their own well-being or identities a priority. Independent

coding by two researchers with subsequent consensus ensured rigor. The authors seemed unclear

about doing qualitative work, offering homogeneity, small samples size and lack of random

assignment as weaknesses of the study (Santos et al., 2013). However, in IPA, purposive

sampling of a small homogenous group is preferred (Smith et al., 2009). They also stated they

were testing their psychoeducation group (Santos et al., 2013), but data based on participants

verbal responses to the intervention would have been informative, though not a test.

IPA's intent to provide deep understanding of lived experience is demonstrated in these

studies. In keeping with the thematic nature of IPA, these studies separately identified themes of

balance, loss, preserving the dignity of the PWD, learning to cope, mastery, and role

discrepancy. The CGs in two of the studies spoke of not knowing, meaning, negatives, load, and

challenge; in three, positives in caregiving, and motivation; and in all four, dynamics of and

changes in the dyadic relationship. IPA, by means of deepening understanding, also prompts

questions that open new lines of inquiry. These studies prompt many questions including how

meaning, motivation, and relationship dynamics or other highly salient constructs such as the

family system influence the caregiving experience; how dementia CGs negotiate the changes

they experience a few months after diagnosis and at other transitional times, such as when

initiating coresidence with the CR; and how caregiving mastery is experienced with other

culturally specific CGs. The latter concept, applied when Hispanic CGs were chosen by

Simpson (2010), of being aware that caregiving is culturally informed, can lead to IPA work that

deepens understanding of CGs in cultures that the literature shows cope less well with

caregiving, have more positive outcomes, or experience unique or understudied situations.

Clearly there is not a large body of IPA work in this area and much that it can contribute to

understanding the phenomenon of caregiving. This study hopes to contribute further to that

understanding by considering CGs who appear to have less successful coping, while looking at

their meaning-making, relationships, and the family system during a transitional time.

Chapter Summary

Offspring dementia caregiving is an inherently transitional experience as dementia

progresses and the person the CG has known throughout life changes. It thus has clear

challenges and many CGs experience negative mental health outcomes. It is also true that the

experience can engender a new sense of self, coherence, and meaning, both situational and

related to ultimate spiritual meaning. The role of religiosity and its strong associations with

primarily positive CG outcomes suggests that existing societal and caregiving systems may

better serve CGs by incorporation of religious communities into services provided. Outcomes

for the many studies discussed here were biological, psychological, social, and spiritual in

nature, addressing the whole person of the caregiver and, while studies specifically focused on

CRs were not included, their personhood was often recognized. The current study addressed CG

needs, but it did so in part because the well-being of the CR is also at stake.

That the phenomenon of interest is complicated is reflected throughout this literature review and in the many interaction effects noted, such as that finding meaning was associated with religiosity and sense of competence in concert (Quinn, Clare, & Woods, 2012). Findings were often differential by race and ethnicity, gender, coresidence with the PWD, and relationship to the CR. Additionally, dementia CGs negotiate caregiving within a fragmented caregiving system which the U.S. societal system is trying to address. Embedded in those systems, CGs engage in dyadic relationships of great personal significance in a sometimes-conflicted family system that at times contributes to the burden of caring. Few true psychotherapy interventions have been examined for their impact on CG outcomes. A notable exception, the NYUCI, benefitted spouse and offspring dementia CGs, but, adding to the multifariousness of the phenomenon, offspring CGs did not accept the intervention in its original form (Gaugler et al., 2013)

The complexity lends itself to input from qualitative studies, several of which have shed light on this discussion. Specifically, IPA has the potential to deepen understanding of important and complex human phenomenon such as offspring dementia caregiving and, with the many lines of inquiry in need of deeper understanding as suggested by this literature review, IPA has important contributions to make to the field. The current study was designed to deepen understanding of the offspring dementia caregiving experience for European American coresident daughter CGs, for whom the evidence suggests there is greater likelihood of negative outcomes, with awareness of their struggle to make sense and find meaning as they operate within family, caregiving, and societal systems. This research process can then be expanded to other diverse caregiving situations.

As the picture of offspring dementia caregiving becomes clearer, it will be more intuitive

to develop and implement effective mental health treatments for the well-being of CGs, CRs, and

the systems of which they are a part. There are efforts being made to find a cure for AD, but it is

not currently forthcoming and such a monumental finding will not likely cure other forms of

dementia. Thus, sadly, the phenomenon of dementia caregiving is not likely to disappear soon.

CHAPTER THREE: RESEARCH METHOD

That the number of older persons needing care, including those with dementia, is increasing while the pool of potential CGs is decreasing creates a situation that threatens greater biological, emotional, social, spiritual, and financial costs to those serving as CGs and the caregiving and societal systems (Farran et al., 1991; Redfoot et al., 2013). Mental health needs of CGs are complex (Lévesque al., 2010), and may be more problematic for dementia CGs, who appear to experience their caregiving journey differently than other CGs (AARP-PPI & NAC, 2015b; Carruth, 1996). There is a need for greater understanding of how best to support dementia CGs (Morgan et al., 2002; Thorpe et al., 2009) and for systemization of services (Feinberg & Levine, 2015). However, for this to occur the voices and insight of CGs are needed. Services and relevant public policy may be more successful in decreasing the burden and increasing the rewards of caregiving when they are based on understanding of CGs' lived experiences, how they find meaning in those experiences, their multiplicity of needs, including mental health needs, and barriers to those needs, (Schulz & Eden, 2016; WHO & ADI, 2012).

This chapter provides explication of the research method for this study that intended to allow the voices and insight of the participant CGs to be heard. The chosen methodology, IPA, is discussed, with rationale for its selection. The choice of participants, methods of data collection and analysis, and assurance of research validity are discussed. Research questions are provided. The context of the study, ethical considerations, and the role and person of the researcher complete the chapter.

Research Design

Research designs should be appropriate for the topic of study (Creswell, 2009). Thus, the discussion below gives the rationale for the choice of IPA and elimination of other methods.

Choice of Interpretative Phenomenological Analysis

Giving voice to dementia CGs leads naturally to selection of qualitative methodology which can lead to deep understanding of how individuals construct their complex, layered social worlds (McLeod, 2011). Qualitative methods are designed to discover (McLeod, 2011), explore and understand inner phenomena (Pistrang & Barker, 2012), and to examine how "aspects of social life are constructed and reconstructed" (McLeod, 2011, p. 17). Mental health, by definition, is an inner phenomenon and the experience of dementia caregiving undergoes frequent construction and reconstruction as the CR's disease progresses and the demands of caregiving change, making qualitative research an appropriate choice.

Among qualitative methods, IPA, designed to explicate how people make sense of and find meaning in their complex lived experience (Smith et al., 2009), is well suited to the study of dementia CGs, for whom finding meaning is associated with better outcomes (McLennon et al., 2011). In addition to finding meaning, identity formation and transformation, especially during times of transition, is an emphasis of IPA (Smith et al., 2009). For offspring dementia CGs, identity, related particularly to their relationship with a parent (Daire, 2004), role discrepancy (Montgomery & Kosloski, 2009; Savundranayagam & Montgomery, 2010), and loss of self (Skaff & Pearlin, 1992); and the transition to the caregiving role, the ongoing transitions as CR dementia progresses (Montgomery & Kosloski, 2009), and transition to coresidence suggest a rich experience that IPA can elucidate. IPA stands out among qualitative methods for its explicit focus on inner experience (Pistrang & Barker, 2012). The prominence of meaning-making, identity formation, and interpersonal relationships in the caregiving literature, and findings that suggest CGs' sense of self and beliefs supersede objective burden in their impact on CG mental health outcomes (Montgomery & Kosloski, 2009; Savundranayagam & Montgomery, 2010;

Simpson & Acton, 2013; Skaff & Pearlin, 1992) give import to dementia CG inner experiences. The philosophical underpinnings of IPA are holistic (Smith & Shinebourne, 2012), analogous to the biopsychosocial-spiritual person of the caregiver (Farran et al., 1991; Smith & Harkness, 2002), under consideration in the current study. The idiographic nature of IPA (Smith et al., 2009) permits respect for the idiosyncratic experience of dementia CGs (Galvin et al., 2016), while promoting convergence and divergence of cases (Smith, 2011b; Smith & Shinebourne, 2012), allowing room for the complexity of the caregiving phenomenon (Galvin et al., 2016).

There is insufficient research on caregiving and the family system (Brodarick, 2014; Qualls & Noecker, 2009), particularly in families that are not functioning well (La Fontaine & Oyebode, 2014); relationship of CGs to the caregiving system (Fortinsky, 2001; Shiba et al., 2016); barriers to access to services (DiZazzo-Miller et al., 2013); caregiving policy development (The Pioneer Network, 2012); mental health of offspring dementia CGs, as the current literature review reflects; and effectiveness of mental health treatments for those CGs (Gaugler et al., 2015; Spijkew et al., 2008). More qualitative research is needed regarding the relational and systemic impacts of dementia caregiving (La Fontaine & Oyebode, 2014; van Hout et al., 2006); interventions (La Fontaine & Oyebode, 2014); how offspring dementia CGs experience their parents' love (Carruth, 1996); the complexity of meaning-making and spirituality in relation to CG outcomes, for which quantitative studies have demonstrated equivocal results (Leblanc et al., 2004; Lopez et al., 2012; Sun et al., 2010); and, again from the current review, the mental health and treatment of offspring dementia CGs. The knowledge gaps related to caregiving and the family system need to be addressed considering that the family is a potential source of CG support (McGoldrick et al., 2008) and the evidence that family is a particular source of CG distress (Coletti, 1997; DiZazzo-Miller et al., 2013; Gaugler et al., 2015;

Suitor & Pillemer, 2007) and one that mental health counselors are trained to treat. IPA, which

seeks to illuminate inner human experience (Pistrang & Barker, 2012), has the potential to shed

light on these gaps in the knowledge base via elucidation of the lived experience of these CGs.

Alternative methods. A qualitative research method was chosen to study offspring

dementia caregiving, as noted, due to the complexity and social nature of the ever-changing

phenomenon, the prevalence of inner experience in the existing findings, and the importance of

hearing the voices of the CGs. IPA was chosen from among many qualitative methods including

grounded theory, which strives to develop theory from participant data (McLeod, 2011). Theory

development is an important goal for dementia caregiving research, particularly related to the

family system, but because of the idiosyncratic nature of the caregiving experience and the

evidence that it is differentially experienced by race and ethnicity (Chiao et al., 2015; Farran et

al., 1997; Kosloski et al., 1999; Mbiza, 2015; Pinquart & Sorensen, 2005), relationship to CR

(Andrén & Elmståhl, 2008b, 2008c; Chappell et al., 2014; Gaugler et al., 2015; Kaizik et al.,

2017; Skaff & Pearlin, 1992), and gender (Perrig-Chiello & Hutchison, 2010), it may be valuable

first to deeply understand these unique experiences. Narrative and discourse analysis methods

provide rich description of participant stories, but the current study sought to understand the

lived day-to-day caregiving experience more than events, happenings, or life episodes provided

by narrative analysis (Creswell, Hanson, Clark Plano, & Morales, 2007). The emphasis in

narrative work on chronology (Creswell et al., 2007) is not highly pertinent to the current study.

Case studies are more contextualized than narrative research (Creswell et al., 2007) and indeed it

is necessary to understand the systemic contexts in which dementia CGs live. The current

research could be deemed a case study of offspring dementia caregiving in multiple individuals,

a valid type of case study (Creswell et al., 2007). The product of case studies is a thorough

description of the complexity of each individual case, identification of themes across cases, and a

report of broad lessons learned from interpretation of the themes (Creswell et al., 2007). The

current study intended to provide rich descriptions, to capture the complexity of the participants'

caregiving experiences, and to engage in interpretative work, but for the purpose of deeper

understanding of the essence of the phenomenon (Moustakas, 1990) rather than learning of

lessons. Lastly, qualitative methods that are participatory, i.e., the researcher becomes immersed

in the experience as a participant-observer, such as ethnography, autoethnography, and

participatory action research (McLeod, 2011), were ruled out. For the current study to be

conducted as autoethnography, the researcher would need to be a coresident offspring dementia

CG and, as is discussed below regarding the role of the researcher, that is not the case.

Additionally, pragmatics preclude ethnography and participatory action research which require

immersion in the phenomenon of interest. The focus in ethnography on social context (Pistrang

& Barker, 2012) is of interest to the current study but is secondary to the individual experience

within its context. The goal of participatory action research, to foster change (Pistrang & Barker,

2012), may be important for dementia CGs, but a deeper understanding of their idiosyncratic

experiences will be beneficial before embarking on work designed to advance social change.

Participants

Because relative efficacy of treatments for CGs by type of treatment or specific CG

situation (Gaugler et al., 2015; Spijkew et al., 2008) is poorly understood and because mental

health treatments are best guided by mental health needs (Sperry, 2010), it is imperative to build

a knowledge base of what the mental health needs are of specific types of CGs. The differential

experience of CGs relative to gender, race and ethnicity, and relationship to CR discussed in the

literature, the potential benefit of understanding CGs with potentially greater mental health

needs, and the IPA recommendation to conduct research with a homogenous group of participants, lead to the choice of participants.

Initial inclusion criteria for participants were that they be European American daughters who are the primary CG for a parent with Alzheimer's disease or a related dementia, with whom they initiated coresidence in the preceding year. Although the goal was to interview CGs who are likely to have greater CGB, those in great distress and potentially in need of urgent mental health services were excluded for their own well-being. Because of the significance of the family system in the caregiving literature and the specific stressors identified in sibling offspring CG relationships, participants were required to have at least one living sibling capable of participating in caregiving. For instance, if siblings of CGs have disabilities that preclude their being able to support the CG, dynamics would be quite different than if siblings are able but are not involved in caregiving as much as the primary CG. IPA utilizes purposive sampling of a homogenous group of participants (Smith et al., 2009). There is some evidence that caregiving outcomes differ based on whether offspring CGs are the same gender as the parent receiving care (Allen, Lima, Goldscheider, & Roy, 2012). For the sake of homogeneity and because the preponderance of older adults receiving care are female (AARP-PPI & NAC, 2015a), making for a larger pool of potential participants, only those caring for a mother were included. Because this is not a comparative study, it only sought to add to the understanding of this select group of highly stressed CGs. It can lay the groundwork to expand the inquiry to other homogenous groups of CGs, in order to clarify their differential mental health needs and identify strengths that may be the source of their better outcomes.

IPA's focus on the in-depth experience of the individual is reflected in its suggestion that researchers conduct four to ten interviews with three to six participants (Smith et al., 2009) or,

for doctoral work, six to eight (Pietkiewicz & Smith, 2014). Additionally, data saturation is not a

specific goal of IPA and is considered to be contrary to the focus on idiography (Brocki &

Wearden, 2006; Dworkin, 2012; Spiers, Smith, Simpson, & Nicholls, 2016) and thus was not a

guiding principle in choosing the number of participants for the current study. Six participants

were recruited to allow for in-depth understanding of each case and to provide sufficient data for

convergence and divergence (Smith, 2011b). Initially the researcher sought to recruit these six

participants though the COAAA, AA-COC, and the Syntero Older Adults Program caregiving

consultant. The intent was to give their case managers the inclusion criteria and ask them to

identify eligible participants and give them the letter of invitation with contact information for

the researcher.

Data Collection Procedures

Prior to scheduled interviews, participants were sent via e-mail the interview questions as

prompts for a diary or for contemplation. At the time of the interviews, participants were sent a

book supportive of dementia caregivers as a token of appreciation. The semistructured interview

form (see Appendix B) was developed from the research question and subquestions. Based on

IPA guidelines (Smith et al., 2009; Smith & Shinebourne, 2012) and the example provided by

Smith and Shinebourne (2012) the interview guide used open-ended questions to encourage

participants to discuss details of their lived experiences of caregiving. Prompts were provided as

needed to deepen the conversation and to enable the participants to explore their mental health

needs, experience of their family systems, including the dyadic and sibling relationships, and

meaning in caregiving. Under the experience of caregiving, the following prompts addressed the

family system.

- What has it been like for you, caring for your mother?

- How has caregiving affected you?

- Do you have needs for yourself that are not being met?

- Tell me about your family of origin.

- Tell me about your relationship with your mother.

- Tell me about your experience of caregiving in regard to your sibling(s).

The final question is related to meaning and making sense.

- What gives your day-to-day life meaning now that you are living with and caring for your

  mother?

The researcher recorded as soon as possible after each interview her recollections, responses, and

observations. This was to provide memory prompts, further contextualize the participant's

experience, and identify aspects of self of the researcher to bracket but was not used for

validation, in keeping with the suggestion that observations of the researcher are not grounded in

the participants' lived experience (VanScoy & Evenstad, 2015).

        After the interviews, the participants were sent measures of constructs shown in the

literature to be highly relevant to the current study and asked to complete and return them in a

stamped addressed envelope. The constructs measured were CGB (Zarit Burden Interview

[ZBI]; Zarit, 2018), depression (Patient Health Questionnaire-9 [PHQ-9]; Spitzer, Williams, &

Kroenke, n.d.), parental bonding (PBI; Parker, Tupling, & Brown, 1979), meaning in caregiving

(FMTC; Farran et al., 1999b), and sibling relationship quality (Lifespan Sibling Relationship

Scale [LSRS]; Riggio, 2000). For assessment of the behavior and cognition of CRs, the CGs

were also asked to complete the 24-item Revised Memory and Behavior Problems Checklist

(RMBC; American Psychological Association, 2018; Teri et al., 1992). Once the instruments

were returned, the participants were sent a $20 Amazon gift card.

The Zarit Burden Interview. A 12-item short version of the ZBI (Zarit, 2018) was chosen as it has been shown to produce psychometrically similar results to the longer version (Bédard et al., 2001) and, when utilized with dementia CGs its personal strain factor was predictive of CG psychological distress (Branger et al., 2016) and to minimize time required of participants. The researchers caution there may be limitations to generalizability of their results for the 12-item version, but for the purpose of the current study, their relative scores for the 25th, 50th, and 75th quartiles of 3, 9, 17 (Bédard et al., 2001) provide sufficient comparison to gain insight into the level of CGB being experienced by the participants.

Patient Health Questionnaire-9. The PHQ-9 (Spitzer et al., n.d.) is a self-administered depression screening tool developed for use in primary health care settings (Kroenke & Spitzer, 2002). This instrument can be used for diagnosis (Kroenke & Spitzer, 2002), but was not used for that purpose here. Instead, it was used to shed light on the emotional distress the participants may have been experiencing. Because the questionnaires were self-administered after the interview and it seemed likely that participants would be at low risk of suicide based on their commitment to their mothers' care and the criteria that those in extreme distress be excluded, the recommendation of an abbreviated research version of the PHQ-9 (Kroenke & Spitzer, 2002) was followed. The PHQ-8 eliminates a question about suicidal thoughts (Kroenke & Spitzer, 2002). To ask that question on paper without immediately available services would be unethical. Also, the measure was set aside until after analysis was complete, causing a potential lengthy delay from the time the participants answered the questions until the researcher saw the responses. The PHQ-8 has psychometric properties similar to the PHQ-9 (Kroenke & Spitzer, 2002).

The Parental Bonding Instrument. The PBI (Parker et al., 1979) was developed from factor analysis as a measure of what the parent brings to parent-child bonding based on an older teen's or adult offspring's recall of their first 16 years of life (Parker et al., 1979). The factors measured are of care versus rejection or indifference and overprotection or intrusion versus autonomy (Parker et al., 1979). The PBI has separate mother and father forms, and the mother form (Parker, Tupling, & Brown, 2017) was used for the current study. The PBI has demonstrated stability over 20 years in a single cohort (Wilhelm, Niven, Parker, & Hadzi-Pavlovic, 2005), suggesting that even though these CGs were long out of their childhoods, the measure appears to capture a stable construct. The PBI care scale was associated with less distress in son CGs (Daire, 2004) and may thus be a relevant factor in caregiving outcomes. It was used to triangulate with the interview data related to the dyadic relationship.

Finding Meaning Through Caregiving scale. Because the FMTC, originally created for dementia CGs, focuses on a primary aspect of the current study, finding meaning (Farran et al., 1999a), its use was of particular value for this inquiry. Somewhat longer than other measures used here with 35 items, it is not difficult and has a simple *strongly agree* to *strongly disagree* format. In addition to the useful subscales of powerlessness and loss, provisional meaning, and ultimate meaning, the FMTC is noted to reflect positive aspects of caregiving and to suggest coexistence of positive and negatives in the experience (Farran et al., 1999a).

Lifespan Sibling Relationship Scale. Measures of adult sibling relationship quality are few. The LSRS is a 48-item measure of adult and childhood cognitions, behaviors, and affects toward a sibling (Riggio, 2000). One study that utilized the LSRS for offspring CGs found that the quality of the sibling relationship was negatively correlated with CGB (Ngangana, Davis, Burns, McGee, & Montgomery, 2016). The LSRS demonstrated good psychometric properties

and the capacity to distinguish between positive and negative sibling relationships (Riggio, 2000). While family systems are complex and cannot easily be captured in a single measure, the use of this instrument provided triangulation and added insight related to the interview data on the sibling relationships.

Revised Memory and Behavior Problems Checklist. The 24-item RMBC assesses CR behaviors related to memory and depression as well as disruptive behaviors and the response of the CG to the behaviors (American Psychological Association, 2018; Roth et al., 2003; Teri et al., 1992). It is a subjective measure of the CG's experience of CR behavior problems and associated burden in the CG (Roth et al., 2003). It has been found to correlate to other measures of distress in dementia CGs (Roth et al., 2003; Teri et al., 1992). While it was designed for measuring CR behavior problems (Teri et al., 1992), it is not an objective measure of those behavior problems. It does fits well with the focus in the current study on the perspective of the CGs and was used to triangulate with the interview data.

Data Analysis

Good qualitative work provides a coherent narrative that reflects the idiosyncrasies of participant data and appropriate interpretation of the data (Elliott, Fischer, & Rennie, 1999). A hallmark of IPA is the double hermeneutic of the researcher using interpretative activity to make sense of each participant's making meaning of the phenomenon of interest (Smith et al., 2009). Thus, the researcher is at times bracketing self to the greatest degree possible in order to enter the participants' worlds and understand their perspectives deeply (Pietkiewicz & Smith, 2014). At other times, the researcher is engaged as self in translating participant meanings in ways that make them accessible and interpreting them in ways that enrich them (Pietkiewicz & Smith, 2014). The capacity to bracket self and enter participants' worlds requires self-awareness to

diminish the influence of bias and to maximize understanding. Bracketing of self is not unlike

the role of a mental health counselor whose training and experience may be particularly well

suited to the work of IPA researcher.

Smith (2011a) noted that good IPA attends to convergence and divergence of

participants, presents findings that are interpretative of themes identified, and must take time to

connect findings to the literature. Indeed, findings that are only themes and quotes from

participants are incomplete IPA (Smith, 2011b) and not enough IPA work in the literature has

demonstrated interpretative activity (Brocki & Wearden, 2006). The process of identifying

themes in the individual cases and across cases is meant to be interpretative at each stage (Smith,

2011a), yet the analytic process in IPA becomes increasingly more interpretative as it progresses

(Smith et al., 2009). With awareness of the interpretative process in mind, this study was

analyzed according to the purposefully flexible guidelines of Smith et al. (2009).

The individual cases. IPA therefore begins with rich descriptions of individual

participants in keeping with its idiographic intent, beginning with a single interview, ideally the

"most detailed, complex and engaging" (Smith et al., 2009, p. 82). The researcher strove for

immersion in the data via multiple readings of the interview transcript and listening to the

associated audio recording (Smith et al., 2009). Because this early engagement with the

interview data was intended to zero in on the participant as primary focus, initial thoughts and

observations of the researcher were recorded in the audit journal and set aside to bracket these

out of the early analysis (Smith et al., 2009). Remaining immersed in the interview data, the

researcher began a deep exploration of the text in order to produce detailed notes that describe,

note the use of language, and observe concepts that arise in "analytic dialogue" (Smith et al.,

2009, p. 84) with each line. These exploratory notes, closely linked to the raw data, were then

analyzed for emergent themes that were both descriptive of the participant's experience and interpretative of it (Smith et al., 2009). Finally, connections and patterns of themes were synthesized and organized, and superordinate themes identified, while remaining open to other ways of understanding, until a sense of doneness was achieved (Smith et al., 2009). The resultant structure was illustrated in a meaningful way and the entire process was recorded in the audit trail journal. The remaining interviews were analyzed in the same way, with effort made to bracket not only the researcher's biases and preconceptions, but also the themes and understandings from preceding cases so that each in turn was understood idiographically (Smith et al., 2009).

Working across cases. The illustrations, notes on themes, and other analyses that were produced in the individual cases were then analyzed for convergence, divergence, and theoretical connections (Smith et al., 2009). In all cases, examples from the participant data were used to support interpretations (Smith et al., 2009). Knowledge from the literature and relevant theory, particularly family systems theory, was incorporated in interpretation at this stage of the analysis. Any resultant interpretations were presented tentatively with clear notation that they are bringing in that which is external to participant experience. Following the suggestions of Smith et al. (2009), the themes were linked back to the original data, to deepen understanding of particular passages and thereby illuminate understanding of the themes. Final tables of themes (see Tables 2 and 3) were produced (Smith et al., 2009)

Assurances of Validity

Qualitative work, done well, must be systematic, grounded in the data, and coherent, with credibility checks and transparency on the part of the researcher (Pistrang & Barker, 2012). Qualitative inquiry should demonstrate sensitivity to context; commitment and rigor; again,

transparency and coherence; and impact and importance (Yardley, 2000). These criteria are all best achieved without losing sight of the creative process (Smith et al., 2009), flexibility, and openness to discovery, which are strengths of qualitative methods (Yardley, 2000), and the personhood of the participants and the researcher. Below, the intent to meet each of these criteria is discussed. It can also be said that readers of the final product will be the judge of its quality (Smith et al., 2009), particularly related to its impact and importance and its rigor when defined as completeness (Yardley, 2000), and they are invited to apply these criteria to the work.

   Grounding in the data and sensitivity to context. Adherence to the criteria were demonstrated first in the interview in which the experience and voices of the participants were prioritized above the research agenda. The sociocultural context of each participant was understood from the choice of CGs, the demographic questions they answered, and the researcher's sensitivity to relevancies from the literature such as stigma associated with dementia. Yardley (2000) conceptualized context to also include what is known in the literature and relevant theory, by which data analysis can be enriched. In that vein, this study is grounded in a literature review that guides the interview questions and the choice of corroborating measures, and it was foundational to the analysis. The empirical and theoretical contexts, however, must not obscure the voices of the participants, even when findings appear to conflict with those contexts, a potentially valuable situation to enrich understanding of the phenomenon (Yardley, 2000). Grounding in the data and sensitivity to context continued in the results via provision of some of the raw data, i.e. quotes from the participants, and discussion of findings which privileged the participants' voices while further grounding the study in the literature and theory. These quotes were used to support conclusions which were presented as an interpretation of the data without undue broad claims the data do not support (Smith et al., 2009).

Coherence and transparency. While IPA is inherently idiographic and the voices of the participants must remain at the forefront, a coherent framework (Pistrang & Barker, 2012) was sought in the interpretative process. That framework and associated interpretations, achieved via extensive analytical work and consultation with academic advisors, is the primary demonstration of the coherence of this study. Additionally, a qualitative work should demonstrate coherence with the chosen method (Yardley, 2000), which in the write up for IPA must include a clear phenomenological approach that helps the reader understand what being an offspring dementia CG is like and provides evidence of the hermeneutic activity of interpretation (Smith et al., 2009). Interpretative activity is not consistently apparent in published IPA studies (Brocki & Wearden, 2006) and the current work strove to produce readily identified interpretations of the data. Transparency allows the reader to know when what they are reading is interpretative and what are the potential impacts of the person of the researcher (Pistrang & Barker, 2012). The former was achieved via clarity of writing and feedback from advisors and the latter is addressed below in the role and person of the researcher where the biases and expectations (Pistrang & Barker, 2012) of this researcher are revealed. The discussion section also includes a self-reflection statement of the researcher based on her experience throughout the research process (Yardley, 2000). Transparency is also demonstrated by delineation of the research process, such as providing the interview guide to readers (Smith et al., 2009). That and other relevant artifacts are appended to this work.

Commitment and rigor. Yardley's (2000) call for commitment in qualitative work entails a thorough deep engagement with the topic and the data, both in collection and analysis. The preceding literature is one evidence that the researcher has engaged deeply with the topic of offspring dementia caregiving. Additionally, the researcher has engaged professionally in the

topic of mental health as a counselor and in dementia and family caregiving as a social worker and is currently engaged personally in the complexities of the family system dealing with parent caregiving. Commitment is also demonstrated by competence in the qualitative method chosen (Yardley, 2000), in this case IPA. The researcher does not claim any experience in IPA, but the necessity in the IPA interview to establish rapport, listen attentively, enter the interviewee's lifeworld, and probe for deeper meaning (Smith et al., 2009) are necessary skills of a mental health counselor learned and practiced by the researcher. Other competencies related to the analysis were supervised by experienced faculty. The intent to and achievement of engaging deeply with the participant data is demonstrated in the above discussions of procedures for data collection and analysis.

The rigor of this study reflects guidance from Smith et al. (2009) to choose participants and conduct the interview purposefully to fit with the research question and that the participant sample be homogenous in keeping with IPA principles. The research question and subquestions and understandings from the literature review guided the development of the interview guide and the choice of a homogenous group of participants. The interview guide, choice of participants, and all procedures and decisions throughout the research process were recorded in an audit trail journal and kept along with artifacts of the study such as the interview transcripts, researcher notes, and illustrations, as one means of demonstrating plausibility and credibility of an IPA study (Smith et al., 2009).

There is some disagreement as to whether triangulation, confirmation of data from additional, typically external sources (Elliott et al., 1999) or via a second research method (Bloor & Woods, 2006), is appropriate to IPA (Alase, 2017; Koch & Harrington, 1998), which does not strongly emphasize this method of verifying rigor (Smith et al., 2009). Triangulation in IPA is

better when the source is participant based internal data (VanScoy & Evenstad, 2015) that is true

to the intent of IPA (Pringle, Drummond, McLafferty, & Hendry, 2011) to explore participants'

lived experiences. In the current study the interviews were the primary data source and

participant journals and quantitative measures of relevant constructs, completed by the

participants, were used for triangulation. This is not meant to be a mixed methods study and the

results of the measures were not analyzed quantitatively. However, after the qualitative analysis

was completed, these data provided confirmation or disconfirmation that the interpretations fit

the participant measures. For example, if the qualitative analysis had found a strong theme of a

given participant finding significant meaning in the caregiving experience, the score of that

participant's FMTC (Farran et al., 1999a, 1999b), would have shed light on the accuracy of the

interpretation or suggest a possible conflict between the participant's verbalization of meaning

and its objective measure. Again, the voices of the participants were privileged, but sources of

triangulation for this study served to challenge the analysis and provided tentative confirmation

of findings without undue claims of validity (Bloor & Woods, 2006).

Despite the concern that using sources external to the participants might compromise IPA

purity, it remains incumbent on the researcher to demonstrate credibility of the interpretation and

conclusions (Pistrang & Barker, 2012). Utilizing member checking, though at times problematic

(Koch & Harrington, 1998; McLeod, 2011), by asking participants to confirm that what has been

concluded corresponds with their lived experiences is the purest way to reinforce validity and

remain committed to participant perspectives. Thus, once analysis was completed, participants

were offered the findings and asked to provide feedback as to whether they believed it fit their

caregiving experience. Feedback was also sought from academic advisors related to the analysis

to validate the logic, challenge the researcher's assumptions, and provide an additional check

that she has been true to the voices of the participants. These advisors were also offered an

abbreviated description of the researcher's audit trail to verify her adherence to the research

design.

Impact and importance. The overarching question of whether a study is of value to the

field (Yardley, 2000) is specifically addressed in determining its impact and importance. For the

current study, the potential exists to increase knowledge and understanding of the experience of

particular CGs, their mental health needs, and the role of the family system in the experience. It

is hoped that by grounding this study in specific experiences of CGs who are likely to experience

significant stress and incorporating findings from the literature and systems theory, that a new

perspective has emerged (Yardley, 2000) that can contribute to the development of mental health

treatments or preventative programs for offspring dementia CGs.

Summary of validity in this study. Balance is of great importance in qualitative inquiry

as there is a need to know if a work has worth (Smith et al., 2009; Yardley, 2000), yet no inquiry

is free of bias and no inquirer unbound by a "sociotemporal framework" (Schwandt, 2002, p. 95)

such that there are no timeless objective criteria to deem a work definitively valid (Schwandt,

2002; Yardley, 2000). This novice IPA researcher chose to err on the side of demonstrating that

this is a valid study, even at the risk of being deemed a *criteriologist,* not to attain an elusive

Cartesian certainty (Schwandt, 2002), which is contrary to IPA's philosophical stance (Smith et

al., 2009). Rather, believing there is an objective truth, but that it can only be known in part (1

Cor. 13:12 New American Standard Version), the researcher accepts the dialectic of needing to

demonstrate the validity of a study which allows readers to know it is worth reading without

making unfounded claims for the research and its findings. This dialectic is in keeping with

IPA's phenomenology that there is a true experience of the CGs and its hermeneutic stance that

recognizes the researcher's attempt to understand that experience is unavoidably an interpretation (Smith et al., 2009). In essence, the researcher was an artist painting what she saw rather than a photographer making a digital recording.

Thus, the efforts made toward demonstrating validity in this study were to provide those who judge its merit what they need to compare the final painting to the original figures represented in the data. No other artist would have ended up with the same work given the exact same data, but others should be able to see the appropriateness of the logic and process by which it was derived. That is then the purpose of this attempt at systematically conducting this study, while leaving room for creativity, with particular focus on the persons of the participants and their words; awareness of the person of the researcher and her biases; and utilization of Yardley's (2000) criteria (See Table 1 for a chart clarifying the criteria).

Research Questions

IPA requires questions that are broad, open, and exploratory (Smith & Shinebourne, 2012) and that explore the participants' thoughts, feelings, and attributional meanings (Pistrang & Barker, 2012). Subquestions should prompt participants to reflect deeply and with detail on their unique experience of the phenomenon (Smith & Shinebourne, 2012).

The primary research question for this study is, "What are the mental health needs experienced by coresident offspring caregivers of a parent with dementia?"

1. How do the caregiver participants describe their caregiving experience?

2. In what ways does the caregiving phenomenon interface with the caregivers'

   experience of:

   a. the societal, caregiving, and family systems

   b. the relationships with the care recipients

      c. the relationships with the caregivers' sibling(s)

      d. the caregivers' sense of identity

   3. How do the caregivers understand and make sense of the caregiving experience?

   4. How do the caregivers' experiences differ from each other and in what ways are they

      similar?

The interview guide was developed from these questions and the interview data were used to seek answers. The process of analyzing the data across cases addressed question number four.

Context of This Study

The evidence suggests that offspring dementia caregiving is a socially and systemically embedded experience appropriate for examination in context (Carpentier et al., 2008; Daire, 2004; Galvin et al., 2005; Sanborn & Bould, 1991). This study was conducted in a time of a rapidly aging population, rising rates of dementia, and consequent increasing demand for CGs. Contributions to CG well-being are important related to personal and societal resources. IPA seeks primarily to explore the experience of the individual (Smith, 2011b), but there is a call to expand IPA to consider the social context of such individual phenomena (Todorova, 2011). Thus, while the focus was maintained at the individual level, data were sought to reflect the participants' experiences within their own family systems and in the caregiving and societal systems. Their experiences also occur within a context of insufficient understanding of dementia CGs' mental health needs to guide effective treatment. This knowledge can be beneficial beyond individual CGs whose well-being enhances that of CRs and of society. The field of mental health counseling is underrepresented in the research and its potential to lessen the clearly identified psychological morbidity in caregiving is yet to be realized. There are subpopulations

of caregivers whose experience is less well understood. Among them are offspring CGs of CRs with dementia.

Beyond the broad contexts of this research are the specific contexts of the participants. Understanding of their situations was obtained via the inclusion criteria, the demographic questions they were asked, the quantitative measures, and any additional information they chose to provide in the interviews. The researcher's observations made after the interviews provided additional context. Thus, the context for this study is the specific situations of the participant CGs occurring within the family, caregiving, and societal systems, with the latter reflecting an urgency to addressing caregiver well-being and mental health needs. A secondary context is that of the researcher, described below.

Ethical Considerations

Institutional Review Board approval was obtained prior to recruiting participants, providing initial clarification that procedural ethics (Guillemin & Gillam, 2004) were built into the study. Awareness of micro-ethics, the not-easily-prescribed decisions *in practice* (Guillemin & Gillam, 2004), were also aspired to by application of training in the counseling profession and ongoing reflexivity and supervision. A strength of qualitative work is the capacity to discover the unexpected (McLeod, 2011; Smith et al., 2009; Yardley, 2000). However, the researcher must be aware that such discoveries could be distressing to participants (Pistrang & Barker, 2012) and may challenge both procedural ethics and micro-ethics. Participants were warned of this possibility and clearly informed that they could end the interview at any time. They were also given the interview questions ahead of time, which may have helped them know if they were comfortable participating in the interview. Additionally, the researcher applied clinical knowledge to awareness of whether to end the interviews, but that was not needed. If there were

evidence of clear and present danger to self or others, the regulations and guidance of the Ohio

licensing board regulations and the American Counseling Association (ACA) code of ethics

(ACA, 2014) would have been followed.

Informed consent included the notation of potential distress in the interview, and the

limits to confidentiality related to danger to self or others, and possible abuse of a child or older

adult. The latter was particularly relevant to the current study and the researcher's obligations

related to "reporting abuse, neglect or exploitation of [an] adult" (Ohio Counselor, Social

Worker, & Marriage and Family Therapist Board, 2018, p. 221) were clearly delineated prior to

initiating the interview. The participants were informed that despite all attempts to maintain

anonymity, there would likely be quotes and extensive descriptions in the publicly available

write up and it cannot be guaranteed that no one could guess their identities. They were told that

they could withdraw from the study at any time up until one month after the interviews based on

the recommendation of Smith et al. (2009) and that there would be no penalty for withdrawal.

They were also told that they would have an opportunity to provide feedback on the analysis.

Lastly, they were informed that, while the researcher is a licensed professional counselor, she

acted in the role of researcher and interviewer and the interaction would not be psychotherapy.

Confidentiality was guarded first by choosing a private location to conduct the

interviews, with the original plan for the researcher to go to the participants' homes or elsewhere

as they preferred. The audio recordings were placed in a locked security box until they had been

transcribed verbatim. They were subsequently erased. The journals and transcripts had all

identifying data removed and transcript codes assigned to them. The participants were given

pseudonyms in the write up.

The original intent was to recruit participants through COAAA and the Syntero Older

Adults Program. The researcher contacted the agencies, explained the study, and asked them to

give their clients who meet the inclusion criteria a letter of invitation. Ethics were attended to

throughout the study, via ongoing reflexivity (Guillemin & Gillam, 2004) and recording of the

process and decisions in the audit journal (Smith et al., 2009). Faculty supervision was also an

ongoing means of monitoring for ethical research.

<div align="center">**Role and Person of the Researcher**</div>

For ethical research, ongoing reflexivity is beneficial (Guillemin & Gillam, 2004; Koch

& Harrington, 1998) and it may be particularly important in IPA in which the researcher overtly

engages in interpretation (Smith, 2011b). This discussion is seen as only a part of the reflexive

process. In the reflexive spirit and for simplicity of text, first person is used throughout the

discussion of the role and person of the researcher. As the study progressed, I engaged in

ongoing reflexivity akin to metacognition (Anderson, 2011), whereby I reflected on my own

thoughts and responses. By continuing reflexivity through the research process, primarily by

recording in the audit trail journal, I maintained an awareness of the more complicated micro-

ethics and more purposively addressed such ethics in practice as they arose (Guillemin & Gillam,

2004). The reflexivity provided shares my "socio-temporal framework" (Schwandt, 2002, p. 95)

with awareness of "moral socio-political contexts" (Koch & Harrington, 1998, p. 887) in order to

provide understanding of my values, assumptions, interests (McLeod, 2011), biases, and

expectations (Pistrang & Barker, 2012), by examining how these influence my construction of

meaning in the research process (Guillemin & Gillam, 2004).

Socio-Temporal Framework

Schwandt (2002) called for researchers to engage in critical reflection, to include

reflection on their socio-temporal framework. For the purpose of such reflection, a discussion of

my professional and personal experience related to the topic of caregiving follows.

Related professional experience. At the time of writing Chapter Three, I worked in a nonprofit mental health agency as an outpatient clinician. I saw clients across the socioeconomic, racial and ethnic, gender identity, sexual orientation, and clinical spectrums. My experience in that setting with CGs was limited. Prior to doing mental health counseling, I worked for 22 years in long-term care as a social worker and often dealt with CGs during times of transition related to caregiving. I witnessed great variety in the quality of the relationship in the dyad, the involvement of the family system, and the resilience of the CGs.

Related personal experience. As a seventeen-year-old just out of high school, my summer job was staying with my grandparents, who were frail and in and out of hospitals and nursing homes, while my aunt worked. I was very fond of my grandparents, but ill prepared for providing physical care. Still, I mostly enjoyed the experience. I specifically remember emptying my grandmother's bedside commode and helping put on her very tight support hose. My grandfather had a small stroke while I was his CG and consequently fell and broke his ribs. No one ever blamed me, nor did I wallow in self-blame, but I always wondered why I did not handle that better.

Twenty-eight years later, my mother was diagnosed with Lewy body dementia. She was frail and very thin. I accompanied her and my father to her doctor visits and my attempts at advocacy for her general practitioner to address her weight fell on deaf ears. My father was her primary CG and I was his support and backup due to my relative proximity and knowledge of elder issues. My mother did not live long after her diagnosis and for a time the CG role was one of emotional support for my father. His good health, strong faith, and active life as a pastor of visitation brought him quite quickly to a place of independence with occasions of breakdown

when life overwhelmed him, at which times he would call me. Those calls often necessitated a quick visit to reassure him and again provide emotional support.

A few years later, after a serious fall that resulted in a hip fracture and a mild heart attack, my father's sister could no longer live safely alone. It was becoming harder for my father to travel four hours to see her, especially in urgent situations such as this. On a trip to visit her in rehabilitation after the fall, he and I agreed it would be nice to have her closer. To our surprise, she agreed and subsequently moved in with me. I used my knowledge of community resources to set her up with support systems and she stayed with me and my teenage son and adult daughter for about a year before moving into assisted living near my father.

Currently, my father continues to live independently, but is needing increasing support, and my aunt remains in a very nice assisted living facility 10 minutes from him. My sister, who lives overseas, calls him daily and helps him greatly with decision-making and guidance and my brother has recently begun helping with various tasks and companionship. Ironically, as I began this dissertation process in earnest, my father had a series of medical and other incidents that entailed increased intermittent responsibilities for me. More recently, and only because I asked the doctor to assess him, he was diagnosed with mild cognitive impairment, and I see sad differences in him. He is beginning to be open to assisted living for himself. I resist embracing the notion that I am truly a CG, in part because I do not carry the heavy load of coresident dementia CGs such as the participants of this study. I have nonetheless found I have felt less patient at times and slightly burdened when his needs conflict with my already overwhelming responsibilities even though my CG role has been very limited. The dynamics of the family system have become more complex and salient with roles and conflicts falling into surprisingly familiar patterns.

I do find positives in the limited CG experience, including feeling honored that my father called me when he had a crisis with my mother and in being able to support him since. I find comfort in having no real regrets after my mother died related to wishing I had done more. I expect no significant regret related to wishing I had done more for my father and aunt when their time comes, though I do feel guilt now that there is not more time to spend with them. I also know I am blessed not to have yet had a heavy caregiving role. I also am able to see where I can resolve some of my FoO struggles via assertiveness and confidence I did not have when I was younger.

Finding meaning in the caregiving experience is complex for me and feels like an incomplete process. The changing and ambiguous role boundaries and resultant frustrations challenge my internalized family values, particularly spiritual ones, in some sense embodied in the family patriarch. Like an adolescent in Erikson's fifth stage, I feel like I am working to create a continuity of self in the midst of role confusion (Koch, Bendicsen, & Palombo, 2009). However, as an adult I have greater capacity to tolerate ambiguity in support of refinement of my worldview. I am surprised by how this limited caregiving is challenging my identity as I strive for more assertiveness, feel dissatisfied with my level of patience, and develop a more nuanced and multifaceted version of my "nice" self. The positive meaning that I am thus deriving from this experience might simplistically be summarized as personal growth, though the trying of my patience often feels negative.

Moral Sociopolitical Contexts

For the current purposes, the feminist understanding of *political* as social power (Watson, 2013) is more relevant than its meaning related to government. For my research, then, the question is, where does the social power lie and how can it be dealt with morally? There is an

inherent power in the positivist researcher-*subject* paradigm, but simply changing the term to *participant* or even *coresearcher*, while more respectful and humanizing, does not fully negate the power differential. The need to protect participants and to attend to nonmaleficence required I was aware of and minimized the power differential and focused on enhancing the voices of the CGs as a means of empowerment.

A secondary aspect of the moral sociopolitical context of the current study that has been troubling to the me is the choice of participants. Historically in the US, research has favored discovery to benefit European Americans with little regard for the well-being of people of color (Reverby, 2010; Richards, 1997). As a European American woman, trained in the sensitivities of social justice and conducting this research in a time of disturbingly overt racist activity that unveils painful racial rifts in American society (Bobo, 2017), I am uncomfortable with choosing specifically European American participants. This unsettling choice is logical based on the evidence presented in the literature review that White CGs have a greater risk of distress and burden and the need in IPA to interview a homogenous group of participants.

Relevant Factors

The preceding discussion situates the researcher with regard to her sociotemporal framework and moral sociopolitical context, providing a backdrop to my interests, assumptions and expectations, and values and biases.

Interests. My interest in the topic of dementia care stems largely from my nursing home experience as I enjoyed working on what are now commonly called *memory care* units and experienced opportunities to run support groups for family dementia CGs. As I contemplated my dissertation topic, I observed several offspring CGs who were experiencing the reignition of unresolved family conflicts. It occurred to me that this might be a situation rich with meaning.

Driven by related curiosity, it was my intent to listen to the participants to discover how they made meaning of their experience, while bracketing my background and interests.

        Assumptions and expectations. Assumptions and expectations must also be bracketed, but first they must be clarified. Relevant assumptions are those related to the choice of IPA, CGs and CRs, family systems, and caregiving and societal systems. In agreement with the assumptions of IPA, I believe that there is a true experience of each individual and that at the same time such experiences are only partially accessible to another. Thus, I worked hard to understand each participant while acknowledging my limitations in doing so. I assumed that caregiving is not easy based on research, experience, and observation, but the literature review bent my primarily negative understanding of caregiving to greater awareness of its potential positives. This again required I be open to the CGs' idiosyncratic experiences. I also made the assumption that navigating caregiving in the family, caregiving, and societal systems is complex and when focused on the demands of day-to-day caregiving, CGs would likely be *making* meaning rather than having *made* meaning. My intent was to consider their process and experience rather than trying to find a neatly wrapped package of clearly defined meaning. It was my hope that the analytic process would bring some clarification to their meaning-making, but I was also open to discovering an unfinished product.

        Discovery is a goal of most research, but unlike quantitative research, qualitative work does not begin with a hypothesis to be tested, but rather attempts to be open to what the data reveal, yet it is unrealistic to think that a researcher does not have some expectations of the inquiry. I am no exception and via professional experience, observations of families making caregiving transitions, and personal experience, I expected that dynamics in caregiving families would likely be complex, and that unresolved family conflicts would impact caregiving and vice

versa (Jacobs, 2015; Titelman, 2003; Wuest et al., 2010). The literature review confirmed that these expectations are realistic. This required me to make a purposeful effort to bracket these expectations and allow these participant CGs' stories to unfold as they experienced them.

Values and biases. I believe in the dignity and value of the individual and the importance of honoring those aspects of people who are marginalized, such as people with dementia, the elderly, and people with mental illness. This study hoped to demonstrate valuing the CRs who were older and had a diagnosis or symptoms of dementia and their CGs who may have been at risk of depression. Part of respect for people's value and dignity is allowing them to be human and flawed, so my intent was not to sugarcoat the CGs' stories, but to privilege their voices as they were. The value of integrity is also important to me and I hope that the discussion of ethics in this study reflects the intent I brought to this research to take integrity seriously. Though mentioned often, the need to bracket, while being honest in the limits of my capacity to set aside my preconceptions, was essential if this was to be an ethical study. The emphasis on reflexivity was an important means of achieving a high standard of ethics and integrity in this work.

Final Reflections

I had no interactions with the participants prior to the research. Had any been recruited from the Syntero Older Adults Program, I would have had an indirect connection as I worked for Syntero. However, I was not involved in the Older Adults Program and did not work with the coordinator of the program. There were no known benefits to me of recruiting participants from the agency. Rapport with interviewees was accomplished using the Rogerian counseling skills of warm positive regard and empathy (Rogers, 2007), functioning as a "naïve but curious listener trying to get to know" (Smith et al., 2009, p. 64) the CGs. Bracketing the above preconceptions and the role of interpretation to the greatest degree possible during the interviews enhanced the

capacity to attend to the participants' words and to enter their worlds (Smith et al, 2009).

Chapter Summary

This research intended to give voice to a select group of six offspring dementia caregivers who were at risk of high burden and potential mental health consequences of caring for their parent, in hopes of providing guidance to improve services and decrease barriers to treatment. The chosen research method, IPA, provides rich, detailed explication of participant interviews focused on meaning and a subsequent analysis of themes within and across cases. The study was guided by the research question, "What are the mental health needs experienced by coresident offspring caregivers of a parent with dementia?" and subquestions related to the CGs' lived experience of caregiving and its relationship to the societal, caregiving, and family systems, the dyadic and sibling relationships, the CGs' identity, and meaning-making. An additional subquestion addresses convergence and divergence between cases. Attention to validity of the study was via grounding in the data and sensitivity to context, coherence and transparency, commitment and rigor, and impact and importance (Pistrang & Barker, 2012; Yardley, 2000). These CGs were providing care in multiple systems within their own specific contexts, while the person of the researcher created a secondary context. For the purposes of validity and ethics and in order to fully contextualize the study, the person of the caregiver, her bents, and values related to the topic have been provided. Further ethical protections, with attention to both procedural ethics and ethics in practice (Guillemin & Gillam, 2004), have been delineated, with particular emphasis on reflexivity and keeping an audit trail journal. It is hoped that the final product of this work provides the reader with a deep understanding of these participants' experience of caregiving.

CHAPTER FOUR: FINDINGS

Research Process

Below is a summary of the processes used in this study, including changes from the research methods outlined in Chapter Three along with justification for those changes.

Participants and Recruitment

Initial participant criteria were non-Hispanic, European American, female, having at least one living sibling capable of caregiving, primary caregiver, coresident, initiating coresidence in the preceding year, caring for a mother, and the CR has AD or a related dementia. Excluded were those in distress and potentially in need of urgent mental health services, under 18 years of age, or the CR has early onset dementia. Initial recruitment was through COAAA and the Syntero Older Adults Program caregiving consultant via asking case managers to identify eligible participants. These sources did not yield any participants. After consultation with the faculty advisor and Institutional Review Board approval of the change in protocol, recruitment, participation criteria, and interview methods were changed. Participants were recruited through the FCA Graduate Research registry; the Counselor Education and Supervision Network Listserv; the ACA listserv, COUNSGRADS; the Association for Adult Development and Aging ACA Connect forum; and via e-mail to Liberty University faculty and counselor education and supervision students. The criteria non-Hispanic, European American, and having begun coresidence in the preceding year were dropped. Interviews via the Internet were also approved by the Institutional Review Board.

Data Gathering

After the interview questions were sent to the participants, interviews were conducted and recorded via Skype and VSee rather than in person. Two participants returned their journals.

At the end of the interviews, participants were given a choice of a book supportive of dementia CGs. The book, along with the packet of questionnaires as described in Chapter Three, were mailed to the participants after the interviews. Five participants retuned the completed questionnaires. After they were returned, the CGs were sent a $20 Amazon gift card.

Data Analysis

This analysis began with a rich description of the participant whose interview was first. While this was a decision made for pragmatics, that participant's interview met the criteria of being "detailed, complex and engaging" (Smith et al., 2009, p. 82). The researcher immersed herself in the data by first re-listening to the recording at which time she took notes that were set aside. She then read through the interview three times without note taking and then repeatedly while making notations in the margin of repeated words, nonverbals, and emerging themes. Additional readings and note taking were done with those themes in mind. Then, through the writing process, the researcher connected and organized the themes until the result had the sense of a complete telling of the participant's story. An illustration of this participant's experience with caregiving emerged and was included as Table 4. Subsequent participants were analyzed by the same process. The categories that emerged from the first participant created the initial structure of each participant's section. For subsequent participant data, as new categories emerged, they were added and, when existing categories did not apply, they were eliminated.

Working across cases. The writings on each participant, including themes that emerged were analyzed across cases, using charts for comparison. Examples from the data were used to support interpretations (Smith et al., 2009) and themes were linked back to the data (Smith et al., 2009). Any resultant interpretations were presented tentatively with words such as *maybe*, *suggest*, and *possibly*. A final table of themes (Smith et al., 2009) is provided in Table 2.

Ann

Ann, the oldest of three sisters, is a European American woman living in the Midwest and caring for her widowed 87-year-old mother who has Alzheimer's dementia. A year and a half prior to the interview, her mother moved in with Ann and her husband, who had moved from out of state a few years earlier to live next door to Ann's youngest sister. That sister still worked full time in a high stress job. A few months before the interview, the middle sister retired and moved into Ann's home to help with caregiving. At the time of the interview, Ann's husband had just recently retired.

The Experience of Caregiving

Ann initially described caring for her mother by comparing it to rearing her children. Her mother "went from being about a five-year-old to now she's about a two- or three-year-old . . . as far as her ability to remember things, to follow directions." The constancy of care, portrayed by the word *always*, reminded Ann of childcare: "always concerned about what they're gonna do, how they're gonna handle the situation . . . if you can take them this place or not that place." The pragmatic and mental-emotional aspects of this caregiving constancy are discussed below.

Mom, the person of the care recipient. While the current work focuses on caregiving from the CG's perspective, the CR at the center of the experience is also important. Ann provided a picture of her mother before dementia symptoms and at the time of the interview.

Past. Ann's mother was "do[ing] something for somebody all the time" due to her life circumstances. She grew up caring for her large family. As an adult, Ann's mother worked fulltime although in the "fifties and sixties [it was] unusual." Ann's mother's mother "was very demanding. My mom had to go to her house every day." Ann "remember[ed] that very much" that her mother "was taking care of her mother . . . a lot," "besides just her three girls" who were

born in a four-year time span. "We didn't demand a lot from her . . . I think because of her

mom." During Ann's childhood, her mother "was very stressed" and "always worried" about

finances and who was going to do what. Ann's mother, "a very strong advocate of . . . be[ing]

able to provide for yourself," encouraged her daughters "to be very . . . good students, active in

anything, to get jobs . . . so that I could pay my way." Ann had "a lot of admiration for her" for

that encouragement. When Ann got married, as she "was the oldest, she kind of moved [Ann]

on. She had others to take care of." Ann expressed no negativity about that. Once her mother

thus "released" her, Ann was geographically distant from her mother, but there were visits and

phone calls. "She was always wanting us to be there" and "interested in what was going on in

our lives," which was important to Ann: "She's your mom and you wanna keep her in touch."

   Present. Because, due to the geographical distance, Ann and her mother had not been

"around one another on a day-to-day basis" and their home was strange to her mother, the

transition to living with Ann was difficult for her. With most memories past the age of 12

"gone," Ann's mother could not recall places she had lived as an adult or "my dad's name." She

did not seem to know Ann is her daughter, rarely calling her by name. "About things that scare

her or, um, hurt her," such as a television show or back pain, Ann's mother was "a bit dramatic."

She has "some back problems when she wakes up in the morning [and] . . . she's like, 'I can't

walk, I can't walk.' And yet, five minutes later, she's fine." Despite this and some "night

dreams" and related behaviors, Ann's mother wa "very pleasant. She's not angry, . . .

demanding," combative, or aggressive. She is content living with them, "she does want to be

here," and she "is gracious most of the time" and "thankful for what she has."

   The pragmatics of caregiving. The constancy of caregiving, "very helpful" supports,

and decisions related to her mother's care describe Ann's pragmatic caregiving experience.

Always. Ann described a constancy of being with her mother who "has to be with you at all times," not even "go[ing] to sleep, um, by herself." Because of her mother's dementia, Ann, her sisters, and her husband "are always just on guard 'cause you never know when the next episode or next downturn might be in her condition." There was constant awareness "of where she's at" regarding both her literal whereabouts, especially at night, and in the disease progression. Ann also verbalized the constant necessity of having to plan ahead for the needs of "day-to-day existence" and having "no freedom to go when you want to . . . without a lot of planning." The constancy of caregiving, "on a day-to-day basis, it gets old, it gets tiring."

Help. To deal with the constancy of caregiving, Ann had both formal and informal help.

Formal help. The year before the interview, Ann's mother began attending a senior center that specializes in working with people with Alzheimer's, twice a week, which was "very helpful," allowing Ann to plan for her own needs and have the "freedom to do" and to go, which "has helped a lot." A dementia care support group provided Ann freedom from guilt related to what she considered lying to her mother. Although she had not gone "for a few months," the group helped her deal with her mother's entrenched beliefs, for instance that a deceased relative was still alive and needed her. Ann came to understand that, because "you can't talk her out of things and . . . tell her things . . . she doesn't understand," it is for her mother's benefit to engage in "therapeutic lies. It's okay." Ann's laughter in this statement indicated a lightness she did not experience when she "had felt so guilty lying to my mom." The support group also reinforced her gratitude as she recognized that her situation "could be a lot worse."

Informal help. Ann did not use the word *team*, but her frequent use of the word *we* suggests she experienced being part of a caregiving team with her sisters and her husband. She was effusive in her gratitude for them and their helpfulness. When caregiving was frustrating, "it

help[ed] to have people around" to "share that same feeling," indulge in humor, "laugh . . . make

jokes between ourselves . . . [make] eye contact and . . . say funny things under our breath," and

"walk away if someone else is here." Ann's team shared caregiving responsibilities and having

her "sister live here has helped tremendously." They also took responsibility for one another

"mak[ing] sure that . . . nobody is getting burned up . . . [or] needs a break" and were attuned to

each other's strengths, "know[ing] one person handles her different ways . . . so in certain

situations we let them take care of it." When pressed, Ann could think of only two conflicts with

her sisters which were "no big deal" and about which, "Who cares at this point?"

  Decision-making. The teamwork carried into decision-making as the sisters were "all on

the same page" and agreed that their mother "not go into any kind of nursing facility." She

elaborated, "Our plan is that she will stay with us." They were "pretty much in agreement about

her caregiving" choices, "her finances," "her medical stuff," and future possible care needs. Ann

believed her mother also agreed with these decisions in her limited way, including the choice of

Ann as the primary CG ("I'm the oldest . . . she always thought I had to take responsibility

anyway") and living with her, as she "would never want to live alone" and, "Though sometimes

she doesn't realize it's family . . . she does want to be here."

  The mental and emotional experience of caregiving. Despite gratitude and her team,

Ann experienced caregiving difficulties, discussed below along with her means of coping.

  Shoulds and guilt. Guilt was a minor aspect of the interview, but Ann expressed past

guilt that she was "lying" to her mother who, when Ann was growing up, emphasized "you tell

me the truth." The support group showed her that telling her mother the truth about things such

as the loved one she believed was alive is dead would be hurtful and "therapeutic lies" are

"really how we have to handle it," helping relieve "a lot of, uh, guilt for me." Ann stated she

"should've done way more of" keeping her mother active outside the house before her team was in place. She sometimes questioned herself regarding activities with her mother, "Am I doing the right thing?" and even about feeling frustrated by her mother's repetition, "which is difficult, I guess."

Dealing with behaviors. Overall "very pleasant," Ann's mother's "night dreams," from which "we have to talk her down," reinforced intractable beliefs such as that her parents or late husband needed her and sometimes led to wandering, once nearly leaving the house. At those times, "you can't talk her out of things," and the "therapeutic lies" were helpful. Ann's mother could be "dramatic" about her own discomfort or television shows that are frightening or hard to understand it, limiting what they could watch. Less dramatically, Ann's mother "would wear the same thing every day [because she] . . . doesn't really tend to notice that they're dirty." Thus, "we have pretty much gone to where we pick out her clothes for her" and "we have to make sure we get [her dirty socks] before she puts them back on." These solutions are simple, but require vigilance, effort, and changing preferred routines. Ann's choice of words to describe her mother's verbal repetition suggests that this may be the most frustrating behavior. "She does repeat a lot, a lot. Every five minutes she'll say that same thing over and over again." When asked how she felt at those times, Ann replied, "Well, it's like oh, not again. Here we go again." In those short sentences Ann's verbiage reflects the concept of repetition, "a lot . . . a lot . . . over . . . over . . . again . . . again . . . again." It also seems to reveal her depth of feeling, which she sums up in the statement, "We all are frustrated. . . . There's nothing you can do about it."

Other challenges. Beyond her mother's behavior, "probably the biggest challenge that I face on a day-to-day basis" is "to have the right spirit to respond to Mom correctly and to meet her needs." Caregiving also challenged Ann relationally. It hindered her relationships with her

adult children who, compared to her sisters, "aren't always quite as understanding," and want her

"to take more breaks," but she "can't go see them" or engage in grandchildren's activities as they

would like. Rather than seeing this as a casualty of caregiving, Ann stated that, "I think that's

been a challenge for me . . . that I want to be friends with my children now they're adults." From

applying what she was learning from caregiving, Ann determined to be more "verbal with

everything, communicating more than I have" with her adult children.

Self-care. Ann recognized a need "to start reading more positive things" for which "I

thought I was too busy." She realized that previously, she "didn't take the time for that." Ann

was "working on that" by signing up for positive devotional emails and "looking for a Bible

study or something for me to hook up with" others, a challenge since she was relatively new to

town, attended a large church, and thus did not "have longtime friends" nearby. Ann valued

"taking care of yourself and making sure that you're healthy, too, to be the good CG that you

need to be." Her team was also "very aware" of self-care and "I appreciate them for that."

Loss. Ann reported a number of dementia and caregiving losses.

Mom. Asked about the emotional effects of caregiving, Ann stated, "I know I've lost my

mother." Related to the mother-daughter relationship she said, "She doesn't really even look at

me as her daughter anymore" and, "In the year and a half that she's lived here, she might've

called me by name twice," but "at this point I've kind of accepted it." It was harder to accept

that "she doesn't have any real remembrance of things that happened," not even Ann's "dad's

name." Thus, "we've lost being able to ask her question about what our childhood might've

been like," an unexpected loss. "I guess I never really thought of it until now that I have

questions about my youth, my childhood and she can't answer them." Ann noted twice the

sadness of the lost memories. "She doesn't remember. At all." She added, "It is hard when you

know that . . . it's gone. Everything you might've had a question about. So that hurts", making

Ann "sad". An additional loss was her mother's capacity to be a spiritual support.   Her mother

had been a "prayer warrior," but no longer "pray[ed] like she used to. Not for us and . . . the loss

of that is kind of sad."

Freedom. Caregiving brought Ann loss of freedom, in part due to household changes. "I

was used to having the house to myself a lot." In the year and a half before the interview, Ann's

mother moved in with her, her sister retired and moved in with her, and her husband, whose job

required frequent travel, retired. Ann expressed only gratitude and relief at having her sister and

husband with her more. Her statement, "I don't have that privacy anymore" was embedded in a

discussion of the demands of caregiving and she followed it with, "I can't even just sit in bed and

read a book." Thus, while her privacy was likely impacted by there being more people in the

house, she focused on the changes in her life due to her mother's dementia and needs. Although

improved by her team and the senior center, Ann talked of loss of freedom to go, do, eat, and

choose what she wants, including her own preference of meal structure or television choices.

Taking a shower, vacuuming or dusting, and reading in bed had become more difficult or

impossible. Loss of freedom vis-à-vis spontaneity was reflected in her reference to the necessity

of planning ahead, "I think it's more just no freedom to go when you want to . . . without a lot of

planning." Buying milk required "you've gotta think about, okay she's here. Is somebody

gonna be with her? If they're gonna be with her, is she comfortable with that?" Before her team

was in place, taking a shower required "planning ahead and figuring out how to do that." Family

visiting "takes a lot of planning" because "when they come here it means moving Mom around"

and travel "just takes a little more planning." It was "a joint effort in preparing and planning."

Personal plans. Ann's retirement plans may not be lost but delayed. Yet related loss "in

what I expected retirement was gonna be like" was "just emotionally . . . not how we pictured

out retirement was gonna be." Ann asserted they "work around what we can" to do some of

what they wanted to do, such as visit children out of state. "We have to plan on when we're

gonna see them," "a joint effort in preparing and planning" with her sister.

Time with next generations. That she "can't go see" her children and grandchildren as

often as she would like "is kind of disappointing for all of us." The "dynamics [of her children

coming to visit] were a little harder to work around, . . . but it works" with her mother staying

with her sister next door. As a result of caregiving and observing her mother, Ann had come to

value the "challenge" of being intentional in her relationships with her children,

> communicating more than I have, . . . be[ing] friends with my children now they're
>
> adults. And I want them to come to me and be comfortable with me. I don't want them
>
> to . . . hide things from me. I want them to feel that I am here for them to talk to and to
>
> be supportive of them.

Thus, in losing time with her children, she was determined to improve those relationships.

Coping with Caregiving

Ann shared a number of ways that she, her sisters, and her husband coped with

caregiving and identified what gives her meaning in caring for her mother.

Tools for frustration. When they "all are frustrated" about her mother's verbal

repetition, "trying to laugh it off" helped. "We just laugh . . . make jokes . . . eye contact . . . say

funny things under our breath that really isn't true." Humor was a way of "shar[ing] that same

feeling." When caregiving felt "old" and "tiring," they would "take [a] deep breath," "go into

the other room for a little while," "pray a lot," or "walk away if someone else is here."

Learning. Ann expressed a strong belief that learning adds meaning to her experience: "I

think if we don't learn, what good are we? Our experiences are here to teach us, so we–we need

to be learning always. That's some of my takeaway from all of this, um, that I'm learning."

After this statement, the researcher asked Ann a question to bring her back to the subject of her

relationship with her mother. She was not dissuaded, though, and returned to the topic of

learning, evidence of its importance to her. She tried "to learn more about the disease, how to

respond, react, what needs to fulfill." Learning about Alzheimer's disease progression was

"interesting" and "it's good to know what might be ahead." Ann recognized the limits of that

knowledge, "Nobody does it [progresses through Alzheimer's disease] the same way. I've

learned that also." The group taught Ann a better way "to approach her," and caregiving taught

her the value of being more "verbal with" her children. She added that spiritually, "we're

supposed to learn to be content with where we're at and with what we have."

Gratitude. Ann followed the preceding statement with gratitude, evidencing that she was

learning to be content. Gratitude was woven throughout the interview, with *appreciate*, *helpful*,

and *thankful* used 27 times, often about her caregiving team. She was thankful her sisters were

"very supportive" and for the harmony with them, "I'm thankful because I know a lot of families

have disagreements." Ann expressed gratitude for where she lives and again her team, "I'm

thankful for my home and where we live and who I'm surrounded by." The spirit of gratitude

carried over to her mother, who "is gracious most of the time", "thankful for what she has," even

for a simple sandwich, and "thankful . . . that she's living here and . . . we're with her."

Accepting, adjusting, and adapting. Ann's statement, "You just start to learn to accept

it and move on" reflects her value of learning and suggests that she saw acceptance as a process.

Ann had learned to accept the inevitability of her mother's disease progression: "I know that's

gonna get worse." In regard to her mother not knowing her name, she said, "At this point I've

kind of accepted" it; and as to being in the caregiving role, she stated, "I am where I'm supposed to be." Adjusting was "a day-to-day thing," an effort to "work around what we can," and a choice. Knowing "there's nothing you can do about" the situation, the behavior, or the inevitable progression of dementia, the only other solution to the frustration, to quit caregiving, had been ruled out by Ann's team. "We're supposed to be doing it." Thus, they were "adjusting . . . and finding ways to deal" with the situation. See Figure 4 for a depiction of her choice to continue care and to adapt.

Trying and effort. Ann and her team did the work of adapting when wanting to "leave the house and go, . . . work[ing] around that a lot". She also used the phrase "work on" or "work around" related to planning for one of them to get away, for their mother's financial and care future, or for having children and grandchildren visit. Even humor necessitated effort in "trying to laugh it off," and self-care required "we all work on that and talk about that together," and "we're working on" planning breaks for each other. Ann was "working on" increasing the positive in her life, demonstrated in the interview when she pulled the discussion toward the positive with an interruption of discussing sadness with, "but on a positive side . . . ."

Self-reminders. That sentence ended, "we always try and remember . . . she's very pleasant." Self-reminders required effort, "trying to keep reminding myself" "that it could be worse" and that "I'm where I'm supposed to be." She reminded herself of the latter "often." In addition to effort, self-reminders required divine help. "It's just a matter of reminding myself and . . . I pray for strength that the Lord remind me of those things."

Philosophical, faith, and meaning-making. Ann's faith, values, beliefs, and things that she is certain of weave together to support her in making meaning of her caregiving experiences.

Where I am supposed to be. Asked what gives her life daily meaning, Ann stated, "just

knowing that I am where I'm supposed to be" and expressed gratitude for where she is living. *Where* was also figurative of her location in life as her mother's CG based on her values: "I really do believe that we do need to take care of our parents" and to "be there for them as much as we are able." The circumstances that brought Ann to where she was, "how things unfolded, what happened," helped her to "know this is where we're supposed to be and what we're supposed to be doing,"

Certainty. Beyond "knowing that I am where I'm supposed to be," Ann expressed certainty with the use of *I know* or *we know* 13 times in the interview. She knew her mother's condition was "gonna get worse" and that "I've lost my mother." She also knew "it could be a lot worse" regarding her family system because "I know a lot of families have disagreements," while they were "very, very lucky" with such a harmonious caregiving team.

One day at a time. Ann used the phrases *day-to-day*, *one day at a time*, and *every day* regarding caregiving 13 times. Smiling, she said, "you just kinda [take] one day at a time. And we're . . . dealing with it. And that's really that's all we've got anyway is one day at a time." Dealing with the challenges she spoke of "the day-to-day existence of" loss of freedom to go; monitoring the "day-to-day things that go on" with her mother; and the "day-to-day" preparing of meals. The meals "every day ha[ve] to be done," and much of caregiving "on a day-to-day basis it gets old, it gets tiring." Yet, "We never know how long it's gonna be and so that helps with the bad things, because you think, 'ugh,' some days. But we don't know what tomorrow brings." She concluded, "So, appreciate today, and, um, make the most of what you can."

Faith. Ann was working to engage more with her faith, learned from her mother, who "encouraged us to go to" church and youth group because "that was important to her," via devotionals, finding a Bible study, and praying "for strength" and "to have the right spirit to

respond to Mom correctly and to meet her needs." Her mother could no longer be a "prayer warrior" on their behalf, but Ann and her team "pray a lot." Her statement, "We're supposed to learn to be content with where we're at and with what we have," reflects a biblical teaching (Philippians 4:11–12), which Ann appeared to be applying through gratitude.

Debbie

At the time of the interview, Debbie, a European American woman, lived in a mid-Atlantic state with her mother who has unspecified dementia and chronic pain. Her husband and co-CG had the previous year taken a job in the Midwest. Because of a decline in her mother's health, Debbie could not move with him. Her mother's home was in an adjacent state where Debbie's sister lives. Her brother, who had lived in yet another state, died two years before the interview. Her father died four years earlier. He was her mother's CG until his health declined.

The Experience of Caregiving

The following discusses Debbie's mother, aspects of caregiving, and her family milieu.

Mom, the person of the care recipient. Debbie did not discuss much of her childhood.

Past. "Mother was always . . . very easy to get along with," "very sweet, patient . . . [but] stubborn," though there were "mother-daughter spats." Before his death, Debbie's father cared for her mother, who had chronic pain, "walk[ed] less and less," could not travel, "spent more . . . time in bed," and was "less social" and "emotionally available," though she "was still engaged" with family. With declining health, both Debbie's "mom and dad become pretty self-centered."

Present. Debbie's mother retained her sweet, patient, yet stubborn personality. "If she's angry. . . . I don't see her lashing out." Being "self-centered" meant her mother was not "a helpful presence" and was unable to converse with Debbie as she "normally would." More focused on immediate needs, she worried ,"Who would take care of her?"

Family milieu. Debbie's FoO was "dysfunctional," and dealing with her siblings was the "difficult part" of caregiving. Yet they "were able to keep it all together there till something happened to the parents." Her father was difficult, but "much easier to get along with in the later years" and impatient, but "that was just him." She stated, "If this were my dad, no, I couldn't" provide care. He had taken "very good care of" her mother, so when he died, "family issues started emerging" and her brother "started going downhill" related to alcohol abuse, which was "incredibly hard . . . to manage and caused a lot of stress and upheaval that didn't need to happen." Still, "there at the beginning . . . we seemed to be able to work well together. . . . We made decisions together."

The roles. Debbie's father predicted their roles and behaviors related to his and her mother's aging, telling Debbie,

> Well, I can just see what's gonna happen . . . your sister, she's gonna just sit there and cry; your brother is gonna ask a million questions and–and have his opinionated, uh, ideas and then just say, "to Hell with all of y'all. I'm gonna do whatever I damn well please."

He added his prediction for Debbie, "and you, you're gonna . . . work."

The responsible one. Debbie "ended up being the one" to determine her parents could not live alone before her father's death, make end-of-life decisions for her brother, and be her mother's CG "because my husband and I are the stable ones." Family expectations and Debbie's choice to step into the gap brought the responsibilities on her. When her father realized her brother had relapsed, he asked Debbie to "talk to him." Dealing with their brother's behavior and his pending death, Debbie's sister adamantly deferred to her. Believing "you can't just sit there and cry when your family needs stuff," Debbie was the "someone in the family [who] has

to enter, has to be there." Though "it's always been that way," Debbie disliked "having to do it all" involving her brother's estate, her mother's legal and health issues, and caregiving.

The pain in the neck. When things were "fine" precaregiving, Debbie's "brother could be a real pain in the neck, so you just never knew what would set him off." When she and her father realized her "brother had started drinking heavily again," they were not "aware of how bad it was." It was "dealing with him" that caused Debbie and her husband to avoid him and eventually to move out of her mother's home and take her back with them to their home. In the end, Debbie only communicated with him via e-mail, unsure "he remembered things" and to have "written records." He made caregiving harder. "If my brother were sober, um, we could have managed it better." She added, "He still would have been a horse's rear end at times."

The struggling one. Debbie was closer to her sister, with whom she has had only two "big argument[s]" in six years of caregiving because they "were always able to talk through it." Her sister's assertions "I can't handle this," "No, I can't handle it," and "I just can't do this. I just can't do this," left Debbie to be the responsible "someone in the family." When their brother "took out his frustration on my sister . . . that just sent her over the edge." When he was dying, Debbie got "a phone call [from her sister] and she's just hysterically crying," leaving Debbie "just having to do it all." When Debbie and her husband moved back to their own home and her mother chose to come with them, her sister's response, "Don't you take my mother away from me," caused one of the two "big argument[s]." Debbie stated her sister was "as stable as she is going to get" at the time of the interview and was not expecting help from her sister, hoping she would remain employed "'cause I don't want another family member to take care of."

Caregiving pragmatics. Constancy and shifts in help framed Debbie's experience.

Always. "Always forget[ting]" despite reminders, Debbie's mother could not "deviate

from her routine . . . 'cause it just throws her," shaping Debbie's life routines. "She likes the same things [to eat] all the time," so "our menu planning has been, um, curtailed" and "our life revolves around meals and . . . doctors' appointments." Things "take a lot of time" because of "the constant questions" and "explain[ing] everything 5,000 times." Further, her mother "always forgets where [they]'re going and why" and, instead of getting ready, "just kinda [sits] there."

Help. Debbie sometimes had paid CGs, and her husband was her primary informal help.

Formal help. The first two years after her father's death, Debbie's mother had round-the-clock paid CGs in her home. At the time of the interview, Debbie was by herself "taking care of my mom with the help of CGs" for four hours on "three weekdays . . . [and] all day Friday." Even with the caregiving help, however, she "really [did] not like" caregiving alone because "it just works better when the two of us [she and her husband] are around."

Informal help. Throughout caregiving, Debbie's husband, who is "really good," had been her primary caregiving support. "As a team, he and I work very well together." When they lived with her mother, Debbie felt supported by friends, people in their church, and neighbors; but "after two years . . . dealing with my brother it just was not working." They returned to their home. "Mom's been up here with us for two years," which was "going fine because my husband was around quite a bit." With his new job out of state, they could no longer "team-tag."

Decision-making. Debbie's husband supported her in decisions, such as moving in with her mother and then back to their home and related to her brother. "At the beginning," her siblings also helped "make decisions . . . together." It became more difficult as her brother denied he had been told things and her sister stated, "I just can't do this." When Debbie asked her sister directly about their brother's end of life decisions, she said, "'No, I can't handle it.'"

The mental and emotional experience of caregiving. Debbie disliked solo caregiving

and, with her husband "would prefer not to be doing this." She described losses in caregiving and "depression and negativity," particularly with "too many things in the mix."

Too much in the mix. Debbie stated, "you throw too many things into the mix . . . [caregiving] doesn't work well, at least from my perspective." The "too many things" included her brother's and mother's "legal and health issues," "deal[ing] with my siblings," her brother's alcohol abuse, her mother's "spend[ing] most of her time in bed" with "other health issues," having to "remember a lot more things," her husband's job out of state, and "having to do it all."

Depression and negativity. Aware of feeling depressed, Debbie chose to address it in the moment. "When I get too negative and too depressed . . . I have to really, like, kick myself in the butt . . . 'Okay, enough grousing'" and "just [do] that whole thankfulness and gratitude." She also addressed feeling depressed by altering her circumstances. She said that when living with her mother and feeling stressed by her siblings, "I saw more depression within myself." They altered those circumstances by moving back to their own home with her mother. Debbie stated that since her husband moved for his new job, she felt "more depressed." Unable to alter those circumstances quickly because her mother "took a downturn," she was planning to make that change soon, "I believe my mother's gonna go back to her home and I'm gonna move" with her husband and end coresident caregiving. Figure 5 reflects these choices.

Dealing with behaviors. Debbie's mother is "very sweet, patient," "easy to get along with," and "it's not her fault . . . she can't retain things," but the repetitiveness was bothersome, reflected by use of the word *repeat* and numeric hyperbole. "Constant questions" required Debbie "explain things and repeat, repeat, repeat, repeat, repeat" and "explain this . . . 10 times," but the explanations got lost because "she forgets." For instance, "She will have eaten whatever it is 20,000 times and she'll look at me and say, 'What is this?' and, 'How do I eat it?'" It was

also bothersome that Debbie's mother could not "deviate . . . from . . . routines" because "it just throws her." Repetition and routine bothered Debbie, who "get[s] easily bored," but "some days it happens more often than others . . . and some days I'm in a better frame of mind."

Self-care. Because Debbie was "get[ting] more depressed," "really d[id] not like" solo caregiving, "it just works better [with] the two of us," and being "here by myself taking care of my mom with the help of CGs" was not sustainable, she was planning for her mother to "go back to her home and I'm gonna move" with her husband. This is an aspect of self-care, valuing personal integrity and "maintain[ing] one's own life story" (Hodgetts et al., 2003, p. 382) that is important since loss of self in caregiving is associated with increased depression (Nichols, 2001).

Loss. When her father and brother died, Debbie lost someone who was not easy "to get along with." In the interview she did not express related grief but shared other losses.

Mom. Debbie's mother was "not really the mother I once knew" in her inability to engage in conversational give and take, or to be an emotional support or "a helpful presence." "That ceased I would say probably a good four years ago." Caregiving caused her role in her mother's life to shift, "I'm the parent, she's the child," describing the loss of her mother as mother.

Personal plans and vocation. Debbie's "biggest frustration" was the impact on "my career trajectory." She stated that what "bugs me the most [is] . . . I'm not quite ready for retirement" and "I probably would have been, um, happiest . . . along the route that I was going six years ago" when she and her husband "had a really good rhythm and we were both doing things we really like." To keep her feet "in the middle," Debbie taught one class online and she planned to re-engage in her career, but she could not act when "positions . . . come up."

Freedom. Prior to the interview, Debbie journaled, "My wings have been clipped." The loss of freedom included not being "free with our schedules," having "our menu planning . . .

curtailed," and "our life revolv[ing] around meals and . . . doctors' appointments." The latter

"take a lot of time" and her mother "can't deviate in–in any way from . . . routines," so Debbie

has "to plan ahead." She also must plan ahead for "time away," suggesting a loss of spontaneity.

Time, a Framework for Caregiving. Time shaped Debbie's experience, in her

references to the short- versus long-term, the day-to-day, and transitions.

Short-term and long-term. For Debbie, "on a short-term basis I think it [caregiving] goes

fine." At her mother's home "there at the beginning," she had a support system and could make

joint decisions and "work well" with her siblings. Even "emotionally . . . early on . . . it was

fine." She and her husband, with only a one-year commitment, had "a rhythm . . . where my

mother lives," but "as it dragged on into two years", she "saw more depression within myself."

After six years of caregiving, the last four coresident, Debbie stated, "something's gonna

happen" to end coresident caregiving. She summed up, "the long-term nature . . . I think is

probably the hardest," and "on a short-term basis this might have been better."

Day-to-day variance. Debbie's mother had "good days and bad days," "sometimes . . .

forget[ing] to get moving," and "some days . . . more often than others" being repetitive. Her

variance**,** whether the professional CGs were present, and Debbie's own variance in "frame of

mind" shaped the "moments where it is fine and moments where it is not."

Transitions. Debbie's transitions occurred when "it wasn't working well." Her father's

health decline, inability to care for her mother, who "was trying to care for him . . . and it just

wasn't working," and subsequent death led to the first transition to distance caregiving with paid

CGs. The next transition was "at the point that family issues started emerging." Her "sister, who

lived in the same town as my mom . . . was starting to fall apart . . . and I decided to move . . . in

with my mother." She experienced another transition when, "after two years . . . dealing with

[her] brother, it just was not working" and they moved back to their own home with her mother.

Debbie was planning to end coresident caregiving as "I really do not like" solo caregiving.

Coping with Caregiving

Debbie discussed what has helped her cope with caregiving and what gives her meaning.

Tools for frustration. Reminder notes for her mother did not work because "you have to actually remember to look at the note" and "I can't like tape it to her arm." For frustration with her brother, Debbie used the tool of only communicating via e-mail. Debbie dealt with her career frustrations by continuing to teach one class online to "keep my feet in–in the middle."

Reframing and finding a rational narrative. Debbie used reframes, particularly humor as a reframe of her situation, laughing 52 times, often at ironies, in the one-hour interview. Reframes included, "The one positive I try to bring up . . . 'Okay, you just have one class to teach and take care of your mother. Look at this as a vacation'" and "It could be worse. It's not a horrible life." Dealing with her brother, Debbie found a rational narrative that his alcohol abuse worsened "after my dad died" and "a lot of the times it was the alcohol that was talking." This helped her, despite the fact "my brother wasn't speaking to me there at the end," to step in and make medical decisions for him; set boundaries ("I'm not talking to him over the phone"); create distance ("We would actually just leave for however long he was there"); and be realistic about his changing ("I can talk to him, but . . . it's not gonna do any good.")

Gratitude. Debbie recognized a need for positivity: "How can we bring ourselves out of this negative?" She answered her own question, "Doing that whole thankfulness and gratitude, um, when I get too negative and too depressed." She was grateful for her mother being "very sweet, patient," and "easy to get along with"; her sister's relative stability at the time; and that "God blessed me with a very good husband" and "as a team he and I work very well together."

Accepting, adjusting, and adapting. With no "grand expectations at this point," Debbie accepted the limits of aging, "Parents are getting older, they can't do what they used to do . . . that's just life" and her brother's being unlikely to change. She accepted, without blame, changes in her parents that were "not necessarily anybody's fault"; her mother's cognition which was "not her fault, she just . . . can't retain things"; and her brother, "it was the alcohol . . . talking." When "bitch[ing] at God" "I don't feel like I'm being a heretic or lightning is gonna strike." Debbie planned to end coresident caregiving rather than keep on adapting. See Figure 5.

Trying and effort. Effort in caregiving for Debbie entailed "strategizing" and "work[ing] through this" when "dealing with" her brother; "trying to explain things" to her mother; working on the "positive [which] I try to bring up into my mind"; and "kick[ing] myself in the butt" to counter negativity. Self-care took effort to "try to keep in touch with, um, friends, . . . try to get to the gym . . . and in nice weather I'll try to get outside."

Philosophical, faith, and meaning-making. When asked about day-to-day meaning in caregiving, Debbie said, "I wish I could say every day I can find meaning, but that's not true."

A long-term view. Short-term, Debbie found limited meaning, but "long-term . . . I will look back without any regrets." Told she was doing "sacred work," she thought, "It's not feeling very sacred, but in the long run I think it will be." As an ordained minister and a counselor educator "this whole experience will inform . . . work I have to do in the future," giving meaning to her interrupted career and hope that her work will be aided by the interruption itself.

Faith. Debbie's "very down-to-earth" "relationship with God" allowed her to "bitch at God a lot" and "after I get through bitching and whining" bring herself "out of this negative" with "thankfulness and gratitude." This was evidence "I'm connecting to God" and was the way she had typically related to Him, stating, "I feel like . . . my faith life . . . hasn't been affected" by

caregiving. Debbie was "no saint" for being a CG and had doubt that caregiving was "sacred."

Purposefully adding meaning. When initiating coresident caregiving, Debbie and her husband "found things that . . . added meaning to our lives," a "support system," "a church that we liked a lot," "the neighborhood folks," and his working on an advanced degree. Debbie purposefully kept "my feet in, in the middle" of her vocation; used time when the professional CGs were there for "the time away that . . . I need"; and chose to engage in self-care.

Sarah

Three years prior to the interview, following the death of her father, Sarah moved her mother, who has dementia, to live with her. Sarah is a European American woman living in a mid-Atlantic state. Her FoO is from the West Coast, where her living two older brothers still reside. One middle brother died "several years ago." When her mother moved in, her two youngest of three daughters, a college senior and a high school student, lived at home. Her youngest daughter, now a college student, still lives at home with Sarah, her mother, and Sarah's husband.

The Experience of Caregiving

Initially "disruptive" and "a big transition," caregiving was still a challenge and fatiguing.

Mom, the person of the care recipient. The transition was also big for Sarah's mother.

Past. On the West Coast, "my mom was very involved in" the lives of "my nieces and nephews, cousins, the rest of the family" and enjoyed "traveling and playing cards . . . and . . . little dinner parties" when she was well and visits and "little outings" after her decline. She was also interested in Sarah's family, inquiring about them over the phone and "thrilled" about Sarah's children's accomplishments. Her mother's decline was more noticeable after the death of Sarah's brother. Sarah had "a pretty good . . . relationship" with and "always felt very

supported by" her parents, with "some conflict but . . . mostly not." Sarah's mother asked each of her adult children, "multiple times to make sure she didn't end up in a home."

Present. Despite the "big transition" moving across the country, Sarah's mother did not seem to miss her home and family on the West Coast. When she spoke of "go[ing] home" she meant "where she was . . . for her first 15 years" of her life. She could not "really answer" simple questions about her day or "connect" like she once did. Sarah, stated, "She's pretty compliant usually," but "occasionally she will be aggressive," adding her mother was "clearly attached to me . . . her primary CG, . . . but occasionally though, she doesn't know who I am."

The pragmatics of caregiving. Sarah experienced the constancy of caregiving although she did have some help. She was both the primary CG and the primary decision-maker.

Always. Sarah's mother was "attached to me . . . more so than anybody else" and Sarah was the one she "[came to] for security." Her mother was "very fixated on having me around," resulting in her being "more agitated" when Sarah was gone. Sarah said that when her daughters stayed with her mother in the evening, "Grandma's not gonna go to bed until I get home." Her mother "need[ed] full-time care" and was diabetic. The "companies that you can hire can't do the insulin," so "mostly it's just me and my mom." This constancy was increasing, "tak[ing] up a lot more time," being "a lot more intense," and requiring Sarah "always . . . be focused on" her mother. "Getting her ready for bed at night is . . . the part of the day where I'm tired, I'm weary, I've had enough" and "I really wish that there was somebody else sometimes that can do the bedtime stuff." Her mother slept poorly and "if she's left her room, the . . . alarm will go off" requiring Sarah check on her. "Even if she has a good night sleep," Sarah worried, "'Why didn't she wake up?' 'Something's not right.'" In the evening, Sarah "encourage[d] her to use the bathroom but she doesn't always understand what you want her to do." Since her mother could

not "get herself up, go to the bathroom, get back in bed," some mornings required "laundry, and sheets, and pillows to change" and "clean[ing] her up." On the day of the interview, "first I cleaned up the cat puke . . . and then I cleaned up my mom." Sarah was able to laugh, but this reflects the constancy of caregiving.

Help. While caregiving was mostly Sarah as the primary CG, she did have some help.

Formal help. "Hired CGs . . . come in twice a week . . . for a couple of hours, and then she goes to a day program . . . twice a week." Sarah's mother complained when arriving at the day program, "Oh, not here again" and "when you pick her up, she's like, 'They never fed me all day long.'" Since as other attenders "start[ed] to leave" her mother got "really agitated," Sarah picked her mother up an hour earlier than required. She was satisfied with the in-home CGs.

Informal help. Sarah's daughters would "usually be the ones that step in" as backup CGs, particularly in the evening. Her youngest daughter, who was still at home, helped with shopping in larger stores. "She's kind of in charge of grandma and I–I'll do the shopping . . . it's better to put two on one if we can." Sarah's cousin, an experienced caregiver, understood her mother's behaviors, was "good with the empathy," and gave Sarah "a lot of support." Though also on the West Coast, "we text daily" and share "the day-to-day stuff." Sarah valued her cousin's responses. "'Yeah, that's a part of life.' So, she's not so much saying, 'Suck it up.' She's saying, 'Yeah, yeah I understand.'" Sarah's brothers could not provide full-time care, but "my oldest brother . . . did all of the precaregiving" and "was so involved" before her father's decline and death. Sharing "legal authority" with him, she tried to "make sure he's kind of in the loop." She stopped sharing "every single detail" with her brothers because it "overwhelms them, there's nothing they can do." She chose to share "the good things and . . . if it's . . . important." If Sarah makes it clear that she "just need[s] to vent a little bit," her oldest brother "can handle that pretty

well." Her brothers "try to be as supportive as they can," texting to stay in touch or ask, "How's

Mom?" and sending occasional "Facebook messages saying, 'Yeah, thank you for all you do.'"

Decision-making. The choice to bring her mother to Sarah's home for care occurred

primarily circumstantially. Two months before her father died, Sarah flew out to be with her

parents, not knowing she would be "there forever" as "somehow in [the next] . . . few weeks I

had become in charge." Sarah was unable to return to the East Coast for her daughter's birthday

until she had arranged a CG for her father. The following week at home, she got calls to manage

her parents' care. Her father died when she was en route back to the West Coast, "so that's kind

of hard." Sarah returned home for another week after hiring a 24 hour CG for her mother, but

her mother became ill and "I was still really involved in her care from here and it was at that

point where I'm like . . . 'she's just gonna have to be with me . . . all the time. . . . I can't

caregiver her from   . . . the other side of the United States [and] . . . I have to be here.' So . . . I

just brought my mom with me." There was no apparent discussion with her brothers, perhaps

because "communication is not a huge thing in our [family] . . . we all live in denial, and we

don't communicate." Sarah "hop[ed] that I've made the right decisions" but they were clearly

her decisions.

The mental and emotional experience of caregiving. Sarah experienced guilt, fatigue,

loss, challenges to self-care, competing responsibilities, and repetitive sameness in caregiving.

Shoulds and guilt. Using the word *guilt* 15 times during the interview, Sarah could "talk

myself down from the guilt usually, but it doesn't make it go away." She dealt with *should*s in

self-care, "you're too tired to do it, but knowing that you should" and in other care, "she's my

job and I should be [trails off], but . . . the rest of my job is . . . trying to take care of my family

and keep all of that" together. When her mother moved in, lack of space meant Sarah's newly

college-graduated daughter "needed to find a job, and a house, and get out." Sarah "felt a little

guilty . . . her transition shoulda been a little bit more . . . slow." She also felt

> guilt . . . hoping that I've made the right decisions [for her mother], knowing that I really
>
> can't meet all of her needs. I can keep her safe, and I can keep her fed, and I can keep
>
> her clean, but I can't always meet the emotional . . . [and] stimulation . . . needs.

Sarah engaged her mother at times, but felt "guilt . . . that . . . I'm not making sure that

something like that is happening every day."

Snatched. Sarah felt "guilty for taking her [mother] away," "pull[ing] her away from her

surroundings," and that "we couldn't bring her dog." She knew "the rest of the family . . . are all

on the other side of the United States," and "my mom was very involved in all of their lives."

Even though Sarah was "the one that can take care of her," she "still felt bad" that "I snatched

my mother and brought her out here." Since her mother's friends were still socializing, Sarah

thought, "If she was back where she used to live, they would visit her . . . maybe take her out."

Universal guilt. Sarah observed universality in CG guilt, "My brother and I . . . both have

the guilt," she "for taking her away" and he "for not being able to" be the CG. Sarah and a

friend with a mother in assisted living, "sort of laugh" because "she feels guilty because she

can't take care of her mother, and I feel guilty." This gave Sarah "perspective" that "there's not

a perfect answer."

Dealing with behaviors. Sarah's mother was "pretty compliant usually" but occasionally

"aggressive." Sometimes "she gets frustrated with me" because "the doors are locked in such a

way that she can't get out." Then, "she'll go from door to door," and "you can't make her

understand that it's for her safety." Her mother knew "she's not free to go" and Sarah

understood "nobody likes to be treated like that." Her mother was redirectable when wanting to

go home: "We'll go, 'Why don't you stay until after dinner?'" or "'Let's have a snack.'"

Sameness and repetition seemed most bothersome to Sarah. "It's hard to have a positive outlook

all the time when . . . every day is gonna be the same" with "not much to look forward to with

dementia" and "the same conversation every day about how she wants to go home." She added,

"There's a lot of repetitiveness in caregiving" which was "overwhelming."

Limited resources. Sarah could not "meet all of her" mother's emotional, stimulation,

and entertainment needs because of her mother's limited capacities and her own limited

resources. When her mother "was sick . . . she [could not] tell me and . . . she got very sad . . .

so I put her to bed and she'd be crying," which left Sarah feeling "untethered because I can't do

anything for her." For stimulation, it took "a lot of energy and a lot of effort . . . to interact . . . in

a way that's gonna . . . help her . . . to respond." Sarah tried to do "little things" to make her

mother "smile and be happy," but "if I'm exhausted, they don't . . . happen." Energy was a

"depleted" resource for Sarah due to disrupted sleep and her mother's needs being "so

overwhelming." She felt "beat. I am exhausted. I don't wanna interact with my mom, I don't

wanna interact with my family" even on a day she engaged in self-care. Sarah referenced

exhausted twice, insufficient *energy* three times, *weary* four times, and *tired* six times. For

example, "Some days I'm like . . . just tired" and, "Getting her ready for bed at night is . . . the

part of the day where I'm tired. I'm weary, I've had enough."

Challenges. Sarah began caregiving with pulls in opposite directions flying back and

forth across the country to be there for her parents and to come home for one daughter's birthday

and another's spring break and college graduation. When at home she "was still really involved

in her [mother's] care from here" and when her father was dying, she "didn't make it. . . . I was

in flight when he passed away." When her mother moved in, "we didn't really . . . have the

space for her" and her "youngest child ended up moving out of her room . . . sleeping on the

floor in the living room, because . . . it just wasn't working out for her and her grandma to share

a room." The challenging transition "pushed my older daughter out . . . of the house fairly

quickly." That time of "upset of . . . the family household" reflects balancing "she's my job"

with "the rest of my job," "trying to take care of my family."

 Self-care. Knowing "you can . . . arrange to have your needs met" and "there are things I

can do that will help me to be in a better place to have my needs met" may be insufficient when

"I'm just too tired to do them." Just "knowing what you need to do but not doing it 'cause

you're too tired to do it" means "sometimes you sort of shoot yourself in the foot." Sarah tried to

engage in "social outings," "Bible reading," "my Bible study," going to church, "listening to

good music," and getting a massage, but sometimes she was "just . . . weary, um, not having the

energy even to go and get those needs met." While her mother was at the day program the day

of the interview, she wanted to "sit . . . in the quiet and not do anything," but she met a friend for

coffee as planned. Sarah felt obliged by self-care, "you should do it" and chastised herself at the

end of a day she had engaged in self-care, "You've got no reason to be like this, out of sorts.

You had all the good stuff today." She stated, "that's universal . . . nobody ever has all their . . .

needs met," but "caregiving does, um, kind of exaggerate it, . . . make it less able for you, . . .

less available to have needs met" and "your opportunity . . . is less." Socializing "decrease[d]

quite a bit." Sarah could not take her mother along, not knowing "how she's gonna interpret

things [or] . . . what she's gonna say," making it "harder to, to make connections with people."

 Loss. Sarah's losses were about her mother, freedom, personal plans, and her daughters.

 Mom. Sarah said, "I miss her," seeing her mother was no longer "thrilled" with her

daughters' accomplishments or interested in Sarah's world. Her mother being physically but not

psychologically present, the definition of ambiguous loss (Boss, 1999; Loue, 2008), left Sarah

feeling "loneliness . . . from not being able to connect like that any longer." Simultaneously, her

mother "los[t] another ability . . . another memory." To cope and be emotionally present, Sarah

"distance[d] myself from her . . . a little bit and . . . I know she's my mom, um, but it's almost

better if I'm not thinking of her as my mom." Otherwise, "it's a little more acute . . . I'm a little

more sad and a little less able to . . . carry the, uh, the emotions of the day for her." Sarah added,

"I've switched over from being the . . . child to the parent," loss of her mother as mother.

Freedom. Not free to utilize respite care due to her mother's diabetes and "companies

that you can hire can't do the insulin," Sarah lost freedom to do simple or necessary activities.

Sleep with was "not a priority necessarily." so she got "a whole lot less sleep." When Sarah

cooked, her mother would "stand on the other side of the gate and . . . stare at me . . . for 30

minutes . . . it's just a little disconcerting." The gate was to "keep my mom out of the kitchen

because . . . she'll go in there, . . . touch everything . . . she doesn't have any concept of safety or

cleanliness." Her mother was "not free to go" because of the gate and door locks. Sarah knew

"nobody likes to be treated like that." Thus, dementia took freedom from Sarah and her mother.

Personal plans. Caregiving made Sarah's "a very small, small world" and "social life is

not really, um, an option most of the time." Plans were limited by her mother's being "more

agitated if I'm not around" and her own fatigue. Caregiving altered plans such as Sarah's two

precaregiving part-time jobs and her daughter's transition. "My world has shrunk quite a bit."

Time with next generations. Sarah "felt a little guilty" about her daughter's abrupt

transition and the "household" disruption at the start of caregiving. Her daughters' help was

valuable to her, but she saw a negative impact. Caregiving "changed my . . . ability . . . even to

interact with my kids to some degree" because "I've always got to be focused on my . . . mom."

Coping with Caregiving

Sarah found it "really hard to . . . stay positive" in the sameness and losses of caregiving.

Tools for frustration. Sarah used tools of not fighting the inevitable, observing her mother's enjoyment, distancing herself, and humor. Her mother's going to bed as early as 5:30 p.m. in the winter, being "up and down" during the evening, and "up again when I'm ready to go to bed" was troubling. Sarah learned to stop "fighting the going to bed," stating, "As soon as dinner's over, if she wants to go to bed . . . she can go to bed." Sarah enjoyed positive moments: "Watch[ing] her . . . [enjoy] the music at church . . . she'll sing along" and "kind of bounce along," and "My cats love her [and] . . . fight to sit on her lap. So, that . . . kind of helps." She added, "It's got to be good for her to sit in her chair with the cat." Emotional distancing by "not thinking of her as my mom" helped "carry . . . the emotions of the day for her." Sarah laughed 92 times during the interview, sharing humor related to caregiving and the ironies of dementia.

Gratitude. Sarah noted "there's some good stuff too, but . . . you don't really see the good stuff while you're in the midst of it. You see the challenges, and . . . not really . . . the benefits." She appreciated that in "a little grocery store" her mother was unlikely to "wonder off," which was "a benefit." Her cousin's support and understanding "really helps" and was "nice." Sarah was grateful for prayers and kindness toward her mother by friends and people at her church and "appreciate[d] . . . spiritual support um, from God to sustain me."

Accepting, adjusting, and adapting. Sarah demonstrated she had worked to accept the realities and limitations of caregiving. She noted that she and her mother "both . . . get impatient sometimes so . . . it's not a perfect relationship." It "helps give a little perspective" to Sarah and is "something I hang on to" to realize "we're doing the best we can, um, but there's not, there's

not a perfect answer for this kind of a disease," allowing her to say, "I'm actually fairly proud of

the fact that . . . we can deal with what comes up, um, without freaking out."

Trying and effort. With the dementia progression, caregiving became more effortful for

Sarah. It took "up a lot more time" and was "a lot more intense." Engaging her mother required

"a lot of energy and a lot of effort on my part." Coping itself was effortful as "it's hard to have a

positive outlook all the time when . . . every day is gonna be the same." Sarah's expression

"carry . . . the emotions of the day for her" suggests the unconscious effort of an emotional load.

Self-reminders. Sarah put effort into self-reminders that "This is best for her," "This has

got to be good for her. This has got to be the better choice." Another self-reminder was

"talk[ing] myself down from the guilt." To deal with guilt from bringing "her out here," Sarah

reminded herself, "This is where I live and I'm the one that can take care of her."

Philosophical, faith, and meaning-making. Sarah was motivated in caregiving by

knowing her mother's wishes, her faith, and a measure of certainty. These sources of meaning

were complicated by the negative factors of caregiving that yield "spiritual . . . ups and downs."

Where I am supposed to be. Despite moments of uncertainty, Sarah was doing what she

believed in, knowing . . . we're gonna do our best to keep our word to . . . [not] put her in a

home." She realized that "if I had left her [on the West Coast] . . . we probably would've had her

in assisted living," which her mother did not want. "I brought her here knowing that" the

alternative was assisted living so, "this has got to be the best place . . . to be good for my mom."

Certainty. Sarah knew in dementia "things are gonna get worse. You're gonna lose

another ability . . . another memory." She was "fairly certain that it is God that . . . sustains me

day-to-day" and that "life has value." That belief was hard to reconcile with "know[ing] this

isn't the kind of life that my–my mom would've liked to have led . . . not how she wanted . . .

her days to end." Sarah was sure her mother would not want to be in a facility, reinforcing her thought that "I can treat her probably the best . . . overall, I feel like we're doing . . . best by her."

Faith. Sarah applied the idea of God sustaining her. "Even in those little emergencies" she would say, "'God, I need help here.'" "I don't necessarily . . . hear angels singing in the background, but I do . . . make it through the day." That example and the phrase *fairly certain* suggest a realistic faith. She was supported by her faith community and "praying friends," who "if I'm having a particularly rough day, . . . will lift me up." She added, "I know they're praying for her" mother. When "ladies at church that always come up every Sunday and greet her . . . give her a hug . . . ask her how she's doing," "it just blesses my heart tremendously just to see how many reach out and care for her. . . . That's a sweet thing." In acts of kindness toward her mother, Sarah "can really see how the Lord's working through them to, um, kind of bless us." Caregiving friends at church helped Sarah see "there's not . . . a perfect answer for this kind of a disease" and "you've gotta do the best you can and . . . trust God with the rest."

Penny

Penny's mother moved in with Penny, who lives in the Northeast with her husband and their 11-year-old son, "four years ago. She is 90 and has vascular dementia." Penny, who is European American, has a younger brother "a half hour drive" away and an older brother and sister in the Southeast.

The Experience of Caregiving

Mom, the person of the care recipient. At the time of the interview, Penny's mother was recovering from a fractured knee so that some of her abilities had changed.

Past. Penny's mother, a retired nurse who lived alone for many years, "used to be a really positive person," "was a tap dancer for 75 years," loved "to be outdoors," and did crafts. "A

Type A personality, she always has to be doing." When Penny was a child, her father abused her and her sister and "because of me . . . we took him to court and had him removed from the house." Growing up, Penny was responsible for housework and overseeing her younger brother and her sister since her mother, the "moneymaker", "always worked." Penny "resent[ed] my mother because she never protected me from my father," but "I told her everything. Everything that I felt, and all the ways that she failed me. And she cried, and I cried. . . . After that we started healing our relationship." Seeing herself in her mother in a positive way, Penny stated, "I'm more like my mom," adding, "I give. I'm the caretaker, I'm the nurturer."

Present. Penny stated, "Under it all is the love," though "my mom is a character, let me tell you", both "good" and "trouble." When Penny was gone longer than her mother thought she should, her mother was "resentful and angry." With her "Type A personality," "she's not as good just sitting," "gets up too quickly," and "gets dizzy." With dementia, "she's become more negative and . . . presents it to the world as, '. . . pitiful me.'" However, she is "very generous," making jewelry she "gives . . . away to everybody." Penny noted, "Some things my mom is still good at," "she still reads books," and some things "you need to connect all the dots for her." At the local senior center, she socialized and went to dances even though she "can't quite dance anymore." Penny interviewed in her mother's room. Her mother chimed in, calling her room "my mama den," saying, "tell them" how many descendants she has, and saying Penny's sister took "the brunt of" the abuse.

The pragmatics of caregiving. Penny discussed the constancy of caregiving and help.

Always. For Penny, "the biggest and hardest part" was that she could not "fully relax" when going out "because I always have to think about how many hours I'm leaving my mom alone." She felt "angst" and "a constant burden" because "a piece of me will worry about her the

whole time I'm out." The constancy required "running between my mother's needs, my son's needs, my husband's needs, not to mention my own . . . which always get kind of back shelved." She added, "It's always the worry, and the concern," and "always a press for time." With so many needs "it's all wonderful, and yes, it's all a burden" and "It's full. It's exhausting. It's good." Even her mother's help required vigilance, like doing "dishes . . . she'll fill it up and empty it out," but "then I have to go around and find where she put everything 'cause she can't remember where anything goes." By contrast, "a part of me . . . relaxed once my mom moved in," "she's much more content . . . I'm much more content," but "it's also draining."

Help. Other than adult day care, Penny had limited formal and informal help.

Formal help. Penny's mother went to a senior center "two or three times a week." It was "a big, big help," "a big plus," "incredibly helpful," "absolutely necessary and wonderful," and enjoyable to her mother. Penny was also at "the point where I'm gonna have to hire somebody" as her mother was "not so much" able to be alone anymore and Penny couldn't "always find friends." She wondered, "How do you hire somebody intermittently?"

Informal help. Penny's "siblings [did] not help, at all" and were mostly "out of the picture." Her younger brother, who lived close, could have "arrange[d] something so that I could have the day off, [but] that never happen[ed]." Her sister visited if "we send her a plane ticket" and was "good company for my mom, but she . . . [was] not fully functional . . . emotionally and mentally." When Penny went away with friends, her sister stayed with her mother, but Penny's husband "oversaw . . . things." Her older brother helped with initial caregiving decisions and financial and legal matters and was the "more responsible" sibling. He stayed with her mother when Penny and her family took a cruise, but "he pretty much sat in the chair and ordered pizza and again did not really step up and care for my mom. He was more companion, uh, but not

really helpful." He then "stayed with us for a month" because "he said he was homeless."

Rather than her siblings, Penny's husband and friends were her caregiving team. Her husband "oversaw" the household when she was away, as noted, but he and her son "don't want to see me go on my own." They and Penny each "trie[d] to play cards with her [mother] at least once a day" to help her "to remember and . . . [keep] her engaged and she enjoys it. She says it relaxes her." Her husband took her mother to a school play when Penny was unable to, saying, "I want to take her", about which Penny stated, "Yeah, yeah, yeah. He's good." Still, at times Penny felt overwhelmed by everyone's needs, including "my husband's needs" and sometimes he "vie[s] for my attention." Penny's friends visited so her mother can "socialize with everybody and she gets to know all my friends and they all . . . love her and look in on her." Penny said, "Usually I'll have friends stop in when I'm gone for a few hours." She referred to specific "friends that are retired doctors," who were "great. . . . When they come and stay with my mom, then I don't have to worry."

The mental and emotional experience of caregiving. Penny experienced angst and worry, self-care needs, and losses, but not caregiving guilt, and dealt with the shadow of her FoO.

Angst and worry. Caregiving was "all a burden" at times. Penny experienced angst "if I go out [because] I worry that she's home alone" and "a piece of me will worry about her the whole time I'm out," but not when friends "come and stay with my mom." She planned to hire a CG to further resolve this source of angst and worry. Her mother's insistence that she could go up and down stairs to help with laundry was resolved, but "for a year, it was the ongoing argument and . . . the worry." In the past, her mother did not intervene in her father's abuse and Penny "felt very unprotected and I . . . had hate and angst and frustration and hurt," but she

worked through the relationship to a place of healing. She experienced angst that "I have to beg my younger [brother] to come and visit her" mother with little success. This was unresolved, but Penny accepted that help from her younger brother "doesn't happen," he "hates me . . . there's no way around it," and she and her siblings "don't have each other to depend upon."

The shadow of the family. Penny used the term "under the shadow of the family" and described shadows of abuse that impacted caregiving; past spiritual and emotional work that minimized the impact of the shadows; and healing the relationship with her mother. Being with her siblings "doesn't really happen anymore" as "none of us are really emotionally close and we don't have each other to depend upon. Everyone [is] kind of their own, uh, satellite."

Always the responsible one. Penny, "always the responsible one," "care[d] for my older sister and my younger brother." It was her "responsibility to make sure everybody did their homework, all the chores were done, and . . . I was always her [mother's] right-hand man. . . . I took care of everything . . . I was the mom so she could be the dad." After "we kicked my father out," her mother "depended on me greatly." With the responsibility came blame: "If my mother came home and the house wasn't clean, it was my fault. Never my sister's fault, never my brother's fault." "My older brother is the golden son. He could do no wrong . . . neither [brother] . . . could do any wrong." Her family role led to Penny being her mother's CG. She knew long ago that "I will end up being my mom's CG. I'll be the one that will take her in."

As an adult, Penny moved back from the West Coast because her "mother was getting older and nobody was taking" care of her. Only Penny and her mother took the initiative to "get everybody together" for holidays. Penny took in her older brother for a month when he was homeless and sent plane tickets to her sister, "her husband, and her two sons and their families" so that her mother could see them and "we had nine of them here." Before her mother, Penny

previously had her father-in-law "come and stay with us for a week or two at a time . . . as he was getting older." At the time of the interview, "we go and visit my mother-in-law . . . every week on Saturdays." Penny's responsibilities for her mother went beyond "just the physical caring for my mom. . . . The paperwork is phenomenal . . . the bills and the Medicare and the Social Security and the trust fund." Regarding the latter, her siblings had "no interest in helping. . . . They wanna know about the money, but they don't want to have any of the responsibility."

The self-one. Penny felt that was especially so of her younger brother, "the baby," who is "self-centered, self-righteous, [and] he doesn't understand the big picture." Her mother's choice to "never explain" to him "the reasons why" "we kicked my father out" resulted in his "resenting me for getting rid of his father." Penny reached out to him, but he "hates me . . . there's no way around it, no matter how good I am to him" and "whatever I say is no, no, no, no, and I'm always wrong and he's always right, and you can't have a discussion." Penny's mother provided funds to expand Penny's home to make a space for her mother: "My younger brother was very resentful that I got any money." He surprised Penny by taking her mother on an outing, but "on the way back, he stopped at the bank and had her give him" nearly half of what she gave Penny "because . . . that's the kind of person he is." She was frustrated that "I stand up and I do the right thing . . . and the two, my sister and my younger brother, again, hate me for it and resent me for it." Penny believed "they're jealous of the connection my mom and I have."

The companions. Penny's sense of being hated by her sister was less prevalent than by her younger brother. What predominated was that her sister "isn't capable" and "is not fully functional, like emotionally and mentally." She cannot "drive to the store and go shopping 'cause she'd get lost," remember "there's a store only two blocks away," or "quite get it" that her mother has lost cognitive abilities. She is "good company for my mom," but not "get[ting] the

picture" or functioning as "the adult," could not provide respite. Penny attributed her sister's inability to effects of untreated injuries from her father's abuse, but growing up, her sister "wasn't responsible" or "emotionally mature" and Penny was responsible for her.

Penny's older brother left home when she was eight, and they are not close. He "is the golden son. He could do no wrong," He was more responsible than her other siblings, helping establish her mother's trust, "do[ing] the math" for caregiving decisions, and changing the trust to protect assets after her mother gave her younger brother the large amount of money. Penny acknowledged his limitations, living far away and being 10 years older than her, but when she left him in charge, he "would sit in the chair all day" despite Penny "stock[ing] the refrigerator and giv[ing] out sheets of information and the meds and . . . how the house works." He "did not really step up and care for my mom. He was more companion, uh, but not really helpful."

Shoulds and guilt. Penny's narrative was free of *should*s and guilt, not using the words *guilt* or *guilty* and the word *should* only once when "wish[ing] my brother would help me" with her mother's assets because "we should be investing it so that it build[s] more." Discussing her mother wanting to go up and down steps to help with laundry, Penny stated that if her mother were to get hurt, "I'll never hear the end of it. It'll be my fault," fitting with her being the only one held responsible growing up. Yet she presented free from caregiving guilt, calling herself a "good mom, good wife, good daughter," "not so self-centered," as her siblings, and "the caretaker . . . the nurturer." Certainty "I did the right thing" in caregiving, prior "spiritual growth," "counseling, and . . . dealing with my own demons with my father" may have minimized guilt.

Challenges. Caregiving was exhausting: "I get frustrated and I get exhausted and I wish everyone wasn't so needy." After Penny's mother's fall and fracture, "the need ha[d] become

much greater," with more "physicality" so that "I pretty much had to do everything for her." The

fracture was "getting better," but "there's always a press for time." Penny felt "like I don't have

my own life" in "moments when my son needs me, my husband needs me, and my mother needs

me, all at the same time" and "everyone's on me at the same time. Then I get very upset," She

said at those times, "I get angry and I get frustrated and . . . I curse, or I . . . like, 'Give me a

minute, give me a minute!'" and "I run in the back and hide." Even at those times, "it is what it

is, and we do the best we can." A challenge during the transition to caregiving was the home

addition. It "was supposed to take eight months" but took "three and a half years" and "the

whole house . . . [was] disorganized." During the "god-awful ordeal," her mother "lived in our

den for a while." Then "we moved out of our bedroom and gave her our bedroom because it was

the most secure place and it was right next to a bathroom." After the "state of confusion and

angst, . . . constantly packing things and moving things," it "finally calmed down" and Penny's

mother had "her own space."

Self-care. Penny valued self-care, but it "always [got] kind of back shelved." Taking a

five-day trip with a friend, was "a big to-do . . . a lot of arranging for me" and her husband and

"son of course don't want to see me go on my own." She had attended a knitting class, but "if

I'm gone longer than she [her mother] feels, then she's resentful and angry." Penny got

resistance to her enjoyment of "music. Nobody else likes classical music. I put it on, and I hear,

'turn that . . . junk off.'" When asked about needs that were not being met, Penny replied, "big

time. I mean, big time," followed by a list of projects, likes, and wants at home and out with

others that she could do minimally or not at all. Penny "wish[ed] I had more time to myself,"

noting, "Sometimes I just need downtime." The trip with her friend "did my heart and soul

tremendous good and I'm–I'm almost to the point where I need to do it again," motivating Penny

to seek out a paid CG "so that I can have a little bit more freedom because I need it. I need it.

Yeah. I, uh, I really need it."

 Loss. Penny reported losses but none related to dementia or the next generation. "Happy

that he's getting to know" her mother, she tried to "make it fun for my son."

 Mom. Penny identified ways in which her mother had lost abilities and aspects of herself,

but no related sense of loss. Rather than losing her mother as mother, the role reversal was

ingrained in the relationship and not new to Penny. "We used to tease each other that I think my

mom and I have been through many lifetimes together and we've just exchanged roles."

 Freedom and personal plans. Penny sought freedom as a young adult by moving across

the country where "I felt free, so I ended up staying there," "the only way I could have a life of

my own." She expressed a similar need in caregiving for "more time to myself" because "I feel

like I don't have my own life," planning to hire a CG "so that I can have a little bit more freedom

because I need it." Her personal plans were curtailed because "I take her to all her doctors"; it

takes "a lot of arranging" for respite; and her mother's decreased mobility limited joint activities.

 Privacy. Penny stated, "We lost a big level of our privacy" because "my mom has no

filters anymore" and "anything we've done in our lives becomes this horrible story" that her

mother tells others. "Every little infraction we have in our lives gets reported out to the world."

The senior center helped "because otherwise her whole focus is just on us."

Coping with Caregiving

 Penny shared coping tools, caregiving challenges, effortful adjustment, and meaning.

 Tools for frustration. Getting away and humor helped Penny cope with frustration.

 Getting away. When overwhelmed, Penny got away in the moment, "I run in the back

and hide." Trips and brief times away were enjoyable for Penny, "depend[ing] on . . . who I get

to stay with my mom." She found it "really did my heart and soul tremendous good" when she "took a five-day vacation just by myself, with my friend" to visit another friend.

Humor. By laughing 18 times during the interview, Penny demonstrated, "When you take care of your parents you have to develop a sense of humor." She intentionally brought humor to her mother. "I try and make her laugh. We try and have funnies every day." Penny told a story that occurred when her mother first moved in, the house was being remodeled, and her son was showing her a new toy. "I'm kneeling on the ground with a lap full of pots and pans, things cooking on the stove, and now I have a helicopter wrapped in my head . . . we all started cracking up, like my son, my mother, and I." Penny said, "You can either cry about it, or you can laugh about it . . . so we try and go for the laugh. Not to say we're always successful."

Accepting, adjusting, and adapting. Penny's acceptance was attached to longing. "[I] wish I had more time to myself and I wish everyone wasn't so needy, but it is what it is, and we do the best we can," noting "it's a constant adjusting" to her mother's changing needs. There was also "[constant] adjusting how I care for myself and . . . have time with my husband and my son as well." She planned to adjust to her mother's and her own needs by finding a paid CG.

Trying and effort. Penny's "biggest thing, almost . . . is trying to get her not to do too much," requiring effort to balance engagement and safety. Humor required effort as "we try and go for the laugh" and "I try and cajole her, I try and make her laugh, we try and have funnies every day . . . I try and make it fun for my son," but "sometimes it's very difficult." Transitions took effort such as the home construction and the planned transition to a paid CG. "I'm gonna start to make the phone calls again to see what kind of coverage we can get . . . and start [to] develop that relationship." Before coresidence, "It was a lot of work having her live apart because . . . I'd have to go and check on her and . . . take care of my house and her house."

Philosophical, spiritual, and meaning-making. Penny found meaning in love for her mother and certainty she was doing the "right thing," aided by past spiritual work and healing.

The right thing. Penny's answer to what gives her life meaning in caregiving was, **"**Oh, well, I love her, you know? I love her, and . . . it pleases me to know that she's taken care of and that she's well and that she's healthy." Her mother's life was better with "lots of company, and love all around her, which is good." Penny's husband teased, "'The way you take care of her, she's gonna live to be 100.' But she is much healthier living with us than by herself."

Certainty. That her mother was doing well supported Penny's certainty that "I did the right thing" and her certainty that "I wouldn't want her to be in a facility as long as I can care for her here." The certainties reinforced, "I did the right thing, so that part of me feels right."

Spiritual. Penny referenced past "spiritual growth and meditating and doing deep body work and breath work and isolation tanks and meditation retreats and . . . spiritual growth," "counseling, and . . . dealing with my own demons with my father" that helped her process and move past childhood trauma. Penny shared "a spiritual story" of a "magical time" with her mother. "I asked God for something to remember this trip by" and found owl wings that were "God's gift to me." "My spiritual name was Little Feather" and an owl "is my totem animal." The "time my mom and I spent spiritually" "bond[ing] as . . . two adult women" and Penny's spiritual work helped in telling her mother "everything," which helped "heal" their relationship and continue the love in caregiving. When her mother moved in, Penny had a "deep sense inside of me that . . . became . . . love . . . and peace and became a little more serene."

Jane

Jane, a European American woman, and her 23-year-old daughter moved in with her mother at her request one year prior to the interview. The first half of that year she took her

mother, who has Alzheimer's to visit her stepfather in assisted living until his death. When her

mother asked her to come back and care for her, Jane had been "living out of state" because she

and her parents had "a huge fight, and I didn't talk to them for two years." Prior to that Jane

took "care of both my mom and my dad . . . for five years." She has a younger brother, an older

stepsister, and an older stepbrother.

The Experience of Caregiving

The current caregiving experience, a chance "to reconcile with" her parents, Jane's

complex FoO, pragmatics, mental-emotional aspects, and coping are discussed.

Mom, the person of the care recipient. Understanding Jane's childhood gives insight

into her maternal relationship. Her parents were 19 years old when she was born. "They got

married and . . . [I] have a . . . brother, who is four years younger." Her "dad was diagnosed with

multiple sclerosis" when Jane was three. She "was very parentified" and "would come home

from school and take care of my dad, do his bedpan, . . . take care of my brother. My mom said I

used to put on a full spaghetti dinner at 5:00." Jane's parents separated when she was nine, "the

only time I ever heard them argue." Her father moved "to live with his parents, and uh, he killed

himself while he was there." Her "mom remarried" a year later. "My stepdad . . . raised me

since I was 10, and to me he's Dad really." Her stepsiblings "only lived with us like . . . a

summer kind of thing." Jane's stepfather and her mother "were both heavy drinkers."

Past. Jane recalled little from her childhood about her mother, who taught fulltime. "I

think a lot of it has to do . . . because my dad [birth father] being sick, that I remember so much

of that." Though her mother "was there", Jane said, "I just don't [remember]. I remember

illness. I remember . . . before my dad died my mom collapsing in the grocery store because she

was so exhausted." Jane only knew she sat "in the classroom in her [mother's] college classes"

because "my mom talks about" it. Her adult relationship with her mother was "conflicted" partly

due to alcohol abuse. "About 10 years ago" her mother had a near fatal fall and "traumatic brain

injury." She "quit drinking then and that improved her personality a lot," but Jane still felt

"stress from . . . her." Jane's mother was "the one person in the room who everybody knew,"

"bubbly and joking," "the life of the party," and, "Everything revolved around her." Jane

"always felt like she was very selfish."

Present. Dementia changed the "bubbly" personality and her mother became "so quiet

and she doesn't interact with anybody," one of the physical and mental changes Jane observed.

Her mother was "funny . . . [and] she's not giving me a bad time," another change that made

their relationship "just different" and "better" and Jane "more comfortable with her now." "We

hang out, we go to the movies, we–we walk, we do our meals . . . we do everything" and "get

along well." Her mother's faultfinding and criticism were "not there, not there at all . . . so that's

nice." Jane's earlier caregiving for both parents "was very, very stressful," but the "relationship

has been much better." She noted, "My relationship with my mom is the best it's ever been."

Family milieu. Jane's "conflicted" maternal relationship, parents' "heavy drink[ing],"

childhood parentification and illness, minimal support and negative messages from her siblings,

and two-year estrangement are complex factors in her caregiving experience.

Parents. Jane's parents' alcohol abuse was "probably the hardest part . . . [as] a teenager

and then into the adult" years. Although "I moved out, . . . from time to time, I'd come home

and . . . my dad would fall down the stairs and that kind of stuff." The relationship with her

mother was still "conflicted" even though "quit[ting] drinking . . . improved her personality a

lot." When caring for her parents previously, just hearing her mother come home caused "stress"

about "what's she gonna be upset about, what about this, what about that. . . . That was hard."

Jane "felt like I was always trying to get her approval but never getting it." Her parents "were really important to" her. After the "huge fight" "was the first time in my life I hadn't talked to my parents, ever." Otherwise, Jane talked to them often and "came back all the time to" visit if she did not live nearby. Yet "I never felt like my mom knew me" and it seemed she was "never satisfied." Jane experienced "conflict with myself . . . [and] with my parents" and was "trying like crazy to be perfect." With "plenty of therapy," she learned "you can't ever be perfect really" and parental approval is something "you're never gonna get," "but . . . that's hard." The idea of perfection began in childhood. "I think the main message I got as a child . . . my parents would say, 'Jane's the perfect one' . . . so it was, 'Don't get in trouble.' 'Don't make any waves.' 'Don't have any needs' was the big [one]. . . . 'Don't ever disagree with anything.'" The messages left Jane feeling "I just can't . . . be real."

Birth father. Though Jane was "really, really ill as a child . . . with asthma and pneumonia, in and out of the hospital", her birth father's multiple sclerosis consumed her childhood. Only three when he was diagnosed, she "didn't have the normal kid . . . go play after school" because she was "very parentified, taking care of" him. "Just as early as [Jane could] remember" she was his CG. "That definitely is where the caregiving started." Jane was nine when her parents separated, and her father left and committed suicide, about which she felt an "immense amount of guilt . . . you know how kids have magical thinking. If I had been a better CG, he wouldn't have died. . . . So, it took me a long time to kind of get over that."

Siblings. Jane's only childhood mention of her brother was that, in addition to her father, she had to "take care of my brother." At the time of the interview, he lived "less than 10 minutes away," but "he's not good with, um, stress, . . . sick[ness] . . . illness. . . . It's uncomfortable for him. It's just like with my dad. . . . I saw my dad more in the six months before he died than my

brother has the last couple of years." Jane added, "in his defense, he's . . . got stuff going on, . . . but he was like that . . . before any of that happened." She stated that, "He always does this thing of, 'Oh, you're so wonderful . . . I really admire you'. I would like more help than admiration." They had conflict over their mother's finances and Jane felt she must "always justify" expenditures to him. When she handled a matter instead of waiting for him, he got "kind of mad," asking "'Why didn't you call me?'" Jane responded, "You would be upset if I call you, so I just took care of it."

At the time of the interview, Jane's contact with her "stepbrother [was] nothing" and was minimal with her stepsister since her father's death. There were occasional emails related to lingering business matters, "but that's it." When Jane's father was alive, "for the first . . . few months that I was here", her stepsister paid the bills and "was controlling everything." It was "so hard . . . having to justify . . . my mom needs this, and not even asking for myself. . . . That drove me crazy." When Jane moved back, her stepsister was "super negative," saying "'Oh, you're there with your daughter,'" "'Oh, you guys are gonna be spending more money now,'" and "'Oh, you brought your dogs . . . you're gonna get kicked out now.'" The stepsibling conflict surprised Jane who "always thought we . . . weren't the type" to fight. When Jane "went away to college," she and her stepsister "were roommates for" a semester and they were "together over the holidays and stuff," so Jane "thought we were close." At the time of the "huge fight" with her parents, Jane found out her stepsiblings "weren't close. . . . It felt like it was all a lie," which "was devastating, thinking for 45 years, 40 years . . . I was close to them and find out it wasn't true. [It]was hard." Jane added that it was also "upsetting to my mom" that "neither one of them has called her to ask how she's doing" since her father died.

Estrangement. Jane's current caregiving experience "definitely feels different" than

before when her mother gave "me a bad time," which "was very, very stressful." The "huge fight" that led to Jane not "talk[ing] to them for two years" "was really, really major, after having been . . . near them and taking care of them." It was also "pretty, pretty devastating." During that time, Jane "was so upset, I just was thinking . . . if something happened to them, oh well . . . at this point . . . if they die, I'm not gonna go to their funeral. . . . It sounds really terrible, but that's how I felt." Jane and her daughter took the initiative "to call my mom and . . . tentatively started talking." Two months later her mother said, "'I need you. . . . will you come home?'"

The pragmatics of caregiving. Jane provided a term for the constancy of caregiving, "attached at the hip." She described having little help in caregiving and financial struggles.

Always attached at the hip. Jane's mother was "at that stage where she wants to be with me all the time, every second" and "can't be left alone at all." If Jane was gone, her mother went "out front looking for" her, wondering "'Where's Jane, where's Jane, where's Jane?'" "It's kind of like we're attached at the hip." Since "it's only a two-bedroom place," she and her mother slept "in the same room," creating caregiving constancy at night. "She gets up during the night" and "she's fallen during the night." For Jane, "the nights feel like they're pretty restless . . . because if she gets up, I wake up." Jane tried "get[ting] up at 3:00 in the morning, thinking" she could get some time to herself to "read" or "do something else," but "nope, she . . . feels that I'm up, and she's up. So, I don't ever get that time." The constancy felt "like when my daughter was little . . . I always had to be right there . . . except for with the little kid you can say . . . stay here or do this or do that, and my mom won't listen." Jane tried taking a nap "in the other room," but "immediately . . . she's going through the drawers." Jane did not "feel like I could leave her" at a senior center they attend because "most of the people" are higher functioning and might "get impatient" with her mother.

Help. Jane described caring for her mother with minimal informal or formal help.

Informal help. Asked about caregiving help from her stepsiblings, Jane replied, "No."

Her stepsister had "pa[id] the bills," but "as soon as my dad died, said, 'Here you go.'" Jane's

daughter was "not able to be on her own right now," but she helped Jane by being with her

mother for short periods such as during the interview. Jane's brother, as noted, is "not good with

. . . stress, . . . sick[ness], . . . illness." She stated that "he's the one that's paying the bills now,"

but Jane did not "know how long he's gonna be able to do it because it stresses him too much."

Also, "He'll try and help, like . . . the car breaks down, so he says, 'Oh, I'll come, . . . I'll fix it,'

but then it takes a month for something that should have taken a couple of days." Jane often took

"care of" issues herself and chose not to seek his help, "Why bother asking?" She wished he

would "come and take my mom out for an afternoon" to give Jane a "break" and he had recently

told Jane, "'maybe I'll come over one day and watch a movie with Mom.'" Jane was not

counting on it, "you know, we'll see."

Formal help. Jane went with her mother to "the senior center" for physical and mental

stimulation, "to be doing something, having some social interaction rather than sitting home all

day." Asked whether she benefits, Jane stated, "I do it for her," adding, "Exercise class is good

because I probably wouldn't make myself go," but otherwise "I'd probably rather have the time."

Jane tried an adult daycare that was welcoming to people with cognitive deficits, but "I felt the

people . . . she wasn't where they are. So, she's kind of like in between." Thus, Jane had not

found an acceptable place to leave her mother and give herself a break. The other formal help

Jane hoped for was through "home supportive services . . . to be a paid CG for her." Jane was

"in that process, but I've been here a year and still don't have it" so she had no formal supports.

Finances. Finances were a source of worry and conflict for Jane. "Moving with her, and

I don't have a job or income, so that's been really hard. Not. . . having my money . . . and I'm not independently wealthy. . . so . . . the money is a stressor for sure." Jane had "anxiety" because she had "no savings, no job." She did not "have many needs, but I want to be able to—like last week my phone was off—I didn't have money to pay for the phone" and to "go for coffee with my friend." Financial conflicts occurred when her stepsister "pa[id] the bills . . . and she was . . . controlling everything." After her father's death, Jane's brother took over the finances which was a relief at first, but, she stated, he was "just as bad actually." In both cases, "it's hard because nobody is there in the situation and realizing what's going on . . . so it's always justifying." Jane and her brother have "had a lot of blowups over money, and it's really um, affected our relationship." For that reason and "because of issues I had with my family before," Jane got her brother "to agree to let a third party take over the finances." They were planning on "meeting with a–an attorney." This seemed best because "he can't handle the stress, and . . . he's having a hard time with it" and "I don't want to do it, it's just not worth it to me" to risk further family conflict. It will be "easier if we have a third party do it" and "I think that will help a lot when I don't have to justify every single thing." The pending service that would allow Jane "to be a paid CG" was also a financial solution, but she did not know when it would occur.

The mental and emotional experience of caregiving. Jane's guilt, challenges, losses balanced by important gains, and self-care are discussed.

Shoulds and guilt. Jane's history of striving to be perfect might underly her feeling "guilt-ridden a lot" related to "not doing enough for her" mother. She worried, "How come I'm not more organized?" or "can't . . . do whatever it is I think I should be doing right at that moment?" and, "What if I'm forgetting something?" That worry drove her to "take online classes," read, and "different stuff" to avoid "forgetting something" in her mother's care, which

"overwhelmed [her] with information." Jane chose to "back up and" focus on one thing at a time when she realized "I can't do everything, because . . . it's too overwhelming." She noted, "I'm doing that to myself, nobody is doing it to me . . . it's kind of my nature to be a researcher and try and find the latest and greatest on everything." Her improved relationship with her mother fed "in with the guilt" because Jane was "getting something positive" from "something negative for her" mother.   Jane felt "bad that I'm more comfortable with her now . . . because she's not giving me a bad time." Despite these feelings and her history of childhood guilt after her father's suicide, Jane did not express a predominance of guilt beyond the words "guilt ridden a lot." She used the word *should* once related to caregiving and *guilt* four times. Jane stated "get[ting] along well" with her mother "definitely feels different" and "that's nice."

 Challenges. For Jane, caregiving was "stressful" beyond finances and family conflicts. She had anxiety "about the future" and "what are her needs gonna be," and wondered if she will "be able to . . . take care of them, and then also if I can't, what's gonna happen to me?" Limitations, such as being "without a car for about a month", were a challenge. Jane felt "stir crazy," not "knowing how much longer I can do this," because they "couldn't get out and . . . we were . . . at each other." With the car working, "having the ability just to say, 'I'm going to the store' . . . is helpful." Though formally diagnosed, Jane's mother needed ongoing management of her Alzheimer's. "That definitely is an area of concern for me because her" PCP prescribed medication, but "hasn't had her go to a neurologist . . . so I'm trying to see what our options are."

 Repetition. Challenged by her mother's repetition, Jane said, "It feels like it's Groundhog Day. Yeah. A lot—a lot." She added, "She's forgotten that she's eaten . . . so she's hungry and we have . . . a discussion about the food again" and, "A lot of times during the day . . . she probably has 100 necklaces that she's made, she'll get them all out, look at all of them, show me

each one . . . like I've never seen it before." She followed those statements with, "Now the car is ready, we're ready to go back to the" the senior center, suggesting the repetition may have been more bothersome when they were "stir crazy" and unable to keep her mother "active." Jane dealt with the repetition by "doing mindfulness" and thinking "okay, . . . I've heard that 30 times today, act like it's the first time." She was aware the repetition was an emotional "trigger." Historically, Jane "felt like my mom didn't know who I was and . . . didn't listen to me." "So here you have somebody who's repeating, repeating, repeating and . . . in my head I'll go, 'Oh, she's not listening to me', but then I say, 'Oh, that's right, I'm just getting triggered and this isn't that. This is . . . the dementia.'" Jane can then "process it, but I notice that I get triggered."

Self-care. "Probably the biggest" self-care need for Jane was for "some respite . . . even if it's just for a day or two" and "alone time" because "I'm pretty much, um, an introvert and . . . I need a certain amount of downtime where . . . the TV is not on; I'm not interacting with another human being. It doesn't have to be long, but I need it." Yet "I don't ever get that time." Jane was "trying to figure out how to make that happen," "thinking about that, and trying to figure it out" because "I wanna be able to care . . . for her, . . . but in the past I've done it at the expense of myself and I don't want to do that." She observed "stress in my body" that was "getting more and more. . . . I think part of it is that I need . . . some respite," adding, "When I feel the stress being as high as it is right now . . . I've got to do something different . . . exercise to relieve the stress, or . . . plan[ning] something so I have a day out a week, or . . . something." Jane was "not getting enough sleep" and, per her doctor "it's affecting my health." Though "that one is a hard one to figure out" Jane sought a solution for sleep. She did begin giving her mother "melatonin and that seems like that's helping her sleep more soundly through the night. She doesn't wake as often. If I move on the bed, she doesn't" always wake up, which was "better."

Loss. Jane's caregiving losses came with gains of reconciliation, "my relationship with my mom [being] the best it's ever been," and returning "home," which is "positive." She had "lots of extended family and . . . [her] best friend here." Having been "really lonely" and "missing home," it was "good to be able to be here and see people." The change in her mother's personality helped their relationship, but "it feels really sad" that "she's so quiet and she doesn't interact with anybody" versus her usual gregariousness. Jane noted, "Over the course of the past year, she's been able to do less and less" and, "I see her slipping away . . . in front of me." Her father's death was tempered by being able to reconcile "before he passed . . . yeah, so I feel good about that" and "blessed that we had this opportunity . . . [to] end on a positive note."

Coping with Caregiving

Jane spoke of tools for frustration, trying and effort, and meaning-making to cope.

Tools for frustration. Perhaps because Jane had engaged in "plenty of therapy" and it is her "nature to be a researcher and try and find the latest and greatest on everything," she found ways to apply biopsychosocial tools to caregiving. Noteworthy was awareness of her mother's repetitiveness triggering her and telling herself "this is . . . the dementia and then I'm able to, to just process it." Jane applied self-awareness to "the stress in my body" and the source of stress, without externalizing toward her mother, "My mom's not really different . . . I think part of it is that I need . . . respite." Without an opportunity for respite, Jane used exercise to combat the "stress cortisol," "walk[ing] with her" mother and encouraging herself, "do more. Okay, let's walk two times, three times.'" Mindfulness helped Jane be "more patient." Laughing 27 times during the interview, she used humor for frustration. Since they see "everything at the movies and then . . . TV movies," it is likely they watch comedies. Jane appreciated her mother's capacity to "be funny."

Self-talk. Jane used self-talk to coach herself through stress and alter her thinking and reactions to her mother. When walking, she coached herself "to do more." When she was "overwhelmed with information," Jane told herself, "'just back up and . . . we're just gonna worry on nutrition.'" To deal with repetition Jane told herself, "'I've heard that 30 times today, act like it's the first time'" and "'this isn't that. This is . . . the dementia.'"

Seeing the positive. It was "nice" Jane and her mother got "along well" and "good . . . being able to reconcile with my folks," which was a "bless[ing] . . . [to] end on a positive note." "That part is good . . . having the reconciliation." Returning "home" was "positive" and "fe[lt] good." Even from her difficult childhood, Jane saw positive that "I learned good skills."

Trying and effort. Jane put effort into finding solutions to her caregiving challenges, such as "working with in-home supportive services" to solve financial issues. She addressed her own needs by "thinking about . . . and trying to figure it out" related to anxiety regarding the future, "trying to figure out how to make that happen" for "alone time," and "trying to figure out . . . different things that I can do" for more sleep. Jane addressed her mother's needs by "tak[ing] online classes and . . . reading and . . . doing different stuff" to learn about care, "constantly working on . . . being more kind [and] being more patient," "trying to keep her . . . active," and "trying to see what our options are" to get her mother treated by a neurologist.

Philosophical, faith, and meaning-making. Jane's answer to what gives meaning in caregiving, "giving her the best quality of life that she can have," was also her motivation to do "mindfulness" and work "on . . . being more kind, being more patient." Her mother's "slipping away" motivated Jane to "be as present for her" as possible, suggesting meaning in the moment. Reconciliation gave meaning and was "like I was given a gift" and a "bless[ing]." Part of that gift was that "my relationship with my mom is the best it's ever been." Jane's statement, "I

don't look at it as being a burden or something I don't want to do. I'm . . . glad to do it," an additional source of meaning, is noteworthy in light of the focus in the literature on CGB.

Elena

Elena's mother lived with her for six and a half years after Elena's father died. Elena moved out of state for a fellowship and her mother moved into a senior apartment. When she returned, Elena "noticed that there were issues with her memory." The month before the interview her mother was diagnosed with Alzheimer's and Elena "accepted . . . a job out of town" and moved two hours from her mother. Until then Elena's "role as a CG [was] kind of limited" as her mother was "still relatively independent." Elena has two older half-sisters and an older half-brother, who were born in Central America. Elena, the youngest, is an Afro-Latina who was born in the United States.

The Experience of Caregiving

Elena's caregiving experience was "okay" and "overall . . . really, really . . . positive."

Mom, the person of the care recipient. Elena described her mother and their relationship in the past and in the present dealing with Alzheimer's.

Past. When Elena was a child, her maternal relationship "was really good. I always felt loved." As an adult, "It was still pretty good. At times we clash . . . because I . . . need her help and understanding . . . and I don't get that, . . . but then . . . she has her own limitations, I guess." Elena thought those limitations were from trauma and loss experienced by "everyone pretty much in my family" prior to coming to the US. The trauma and loss were not part of Elena's "extremely ordinary" childhood. Her mother cared for her father prior to his death and Elena "really admired that she cared for my father" because "she was a good CG to him." Immediately after his death, Elena's mother elected to "have hip replacement" she had delayed while he was

living. "It was then that she transitioned from a CG to . . . a recipient of care." Coresident

caregiving, "before she had the diagnosis and . . . after my dad died" "was a bit of a challenge."

     Present. Elena's mother was "still relatively independent," could "still . . . cook [and] do

her activities of daily living," could "walk on her own, sometimes with a cane," and "still like[d]

to assert her independence and . . . her ability to make decisions." She had "just stopped driving"

two months before. Elena's mother "relie[d on her] . . . emotionally more than anything" and

"look[ed to her] for . . . the guiding hand." The transitions of Elena's move and the Alzheimer's

diagnosis were new. Her mother responded to "redirecting," "'Oh, okay,'" suggesting she was

compliant. The diagnosis caused Elena to be "kinder and more patient." In "the little mundane

things like . . . helping her put on [a] shoe . . . or . . . helping comb her hair," Elena had learned

"that I need to be respectful and mindful of" her mother's "physical limitations." The diagnosis

also caused her mother to be "more joyful and happy" "because she's like, 'Oh, okay, now . . . I

have an explanation and an understanding as to what's going on.'"

     The pragmatics of caregiving. Elena did not discuss the constancy of caregiving but

shared an example. Her mother's needs were few and the newness of the diagnosis was salient.

     Not always. Elena's mother was "still relatively independent" and not living with her,

explaining the lack of constancy in her experience. Yet, even during her fellowship, when she

was over 1,400 miles away, "we would talk every day" and her mother "still . . . look[ed] to me

for. . . the guiding hand." Her mother called in the evening while Elena was at her fellowship

and her mother's "breathing was very labored." Elena "tried to reach my siblings who were"

closer to her mother "and I was far away, and nobody answered." Her cousin was visiting her

own mother at the "same complex where my mother lived" and Elena asked her to "check in on

her." Elena's mother "wound up going to the emergency room." From a distance, Elena

managed her mother's care and communicated via text with her siblings. Her mother later said,

"Had it not been for . . . you Elena . . . taking care of things that day, even though you were far

away, who knows what would've happened," demonstrating her dependence on Elena. Elena

described "a bit of role reversal in that . . . she relies on me . . . emotionally more than anything."

Since Elena managed her mother's crises and medical issues when 1,400 miles away, it seems

likely she would continue as "the guiding hand" in her new home 85 miles from her mother.

Help. Elena had little caregiving help other than her brother's reliable involvement.

Formal help. Elena did not reference the use of any formal caregiving help for her mother

other than the medical community. The "senior apartment" had no apparent services. Both a

neurologist and her mother's PCP were involved in the Alzheimer's diagnosis, which Elena

initiated after "notic[ing] that there were issues with her memory." Elena was not able to go to

the appointment with the neurologist when her mother received the diagnosis, but "I was at the

appointment the following day with" her PCP. After a medical procedure, there was uncertainty

whether her mother could travel for a family wedding. That physician told Elena, "She's fine to

travel," demonstrating the value of medical guidance for decisions her mother could not make.

Informal help. Elena stated caregiving was "a shared thing" with her brother who drove

their mother "to a lot of her appointments." His "cooperation, has been just really, really

helpful." Regarding him, she stated, "I know who I can trust and who I can rely on." Before the

fellowship, "even when my mom was living with me", her brother, who lives "the closest," had

been the "one who does a lot of the caregiving, like the hands-on," such as appointments, "'cause

he has a more flexible work schedule." His help predated her father's death when her parents

lived with him and he "provided a lot of additional support." Before Elena's fellowship, her next

older sister suggested their mother live with her while Elena was away. However, "the day that I

told her . . . I got into the fellowship . . . 'so Mom can come and live with you,'" her sister said,

"'Oh, no, that's not a good idea.'" Shocked, Elena realized "it's about . . . modifying

expectations and knowing who you can really trust, who is reliable and who isn't . . . and who's

pretty much all talk." Although "in Latin America[n] . . . culture, . . . usually it's the youngest

girl" who is expected to care for parents, "growing up" she "thought that it would be a shared

responsibility." Elena's believed "my sister's perspective" was that caregiving would disrupt her

privileged life. Caregiving was "primarily between my brother and myself."

 The diagnosis. Elena initiated her mother's evaluation for "issues with her memory."

Though she was not evaluated sooner, Elena said, "I think she–she knew. I think we all knew

something was wrong, but . . . I guess no one really wanted to face it." Elena admitted, "Maybe

it was a little bit of denial on my part," but "it's not that I was necessarily in denial . . . the signs

are there. You just kind of ignore them and say, 'Okay, well . . . that's life; it's part of aging.'

But it's not . . . a natural part of aging." She knew this from her fellowship and "work[ing] in

aging." Her knowledge meant she expected the diagnosis and gave her "an understanding of

what to expect" with Alzheimer's. When her mother "finally had the diagnosis," she told Elena,

"'Well, thank you . . . for making me aware [of] what's going on.'" Having "an explanation and

an understanding" helped her mother be "more joyful and happy." For Elena, "just putting a

name and a label on . . . what's going on has provided . . . relief" and motivation to "put into

action" necessary things "like . . . advanced directives and . . . power of attorney."

 The mental and emotional experience of caregiving. Elena referenced little guilt and

few *should*s. She was "not angry [or] bitter" partly from self-care work she did that

"enlightened" her. Her caregiving challenge was relational, and she had few caregiving losses.

 Shoulds and guilt. Elena did not use the words *guilt* or *guilty* and used *should* only

related to her mother "going to the emergency room" with difficulty breathing. Afterward,

Elena's sister, who had previously told Elena, "'Don't call my house after 10 o'clock'" and who

was not at home at the time, told Elena, "'Well, you should've called my house' [because] . . .

her husband and her daughter could've gone over." Elena had texted her siblings "throughout

the night" and "at three a.m. was the last text that I sent." She "had been talking and texting" her

cousin who was with her mother "but I hadn't included her in the text[s] to my siblings." Her

cousin questioned Elena the next morning, "'Have you heard from your family? Have you

talked to your family?'" Elena felt "blamed for not communicating with them" and questioned

herself about only calling her sister's cell phone, "Maybe I should've" called her sister's home

phone. "By the time I could've called . . . it was late, and I didn't want to bother her family,"

adding "What I should've done was I should've included [her cousin in] my text message to my

family . . . so that she could see that I was doing like essentially a play by play."

Challenges. Elena verbalized no burden and little challenge in caregiving. After

describing caregiving as "a positive experience," she said it "is kind of weird to say this, but . . .

it was a bit of a challenge . . . earlier on when she was living with me . . . before she had the

diagnosis . . . after my dad died." Elena was no longer coresident with her mother and was not

experiencing caregiving as "a bit of a challenge," suggesting that for her, the coresidence was the

hard part of caregiving. There was also "a bit of a challenge with" her siblings.

Relational. When asked, Elena asserted "I really don't think our [sibling] relationships

changed all that much as a result of the caregiving," "I don't think so." She noted negative

changes in her relationship with her next older sister "since my father's death," which was also

the beginning of caregiving for her mother. Based on her descriptions of the sibling dynamics in

caregiving, the interviewer asked Elena whether caregiving had shaped her knowledge or sense

of who amongst her siblings she can count on. She replied, "Yeah. No, that's true. That's absolutely true. Yes. That is true, . . . but then I mean I guess it was always there kinda." To the follow-up question, "Do you think that this process of caregiving has made you just more aware of the dynamics with your siblings?", Elena answered, "Yeah. No, yes. The answer is yes." The challenge with her siblings played out in Elena's story of her mother being short of breath and "going to the emergency room" when "my siblings who were much closer weren't able to provide her with the care she needed." Familial and cultural expectations also added to the sibling challenge. "In Latin America . . . usually it's the youngest girl" who provides parent care and generally, "there is an expectation" of offspring to care. Yet Elena grew up in the US thinking "it would be a shared responsibility." From her next older sister, she got the message, "You take care of Mom. You're mom's CG." There were apparent discrepant expectations of parent care amongst Elena and her siblings. "We just kind of see things differently."

Elena felt "kind of excluded by" her next older sister even though "we were all raised as siblings . . . and everyone would go back to [Central America] to visit the family" and "we were all . . . the same." She felt that "since my dad has died—it's very subtle—I see that she kinda treats me differently. . . . [like] I'm not a full sibling." This dynamic "wasn't all that obvious when I was younger growing up," just "since my father's death." When this sister had a birthday party for Elena's mother a few months earlier, the sister spoke of her own biological father, "but she never really mentioned my dad. You know, the one who raised her, the man who paid for her college tuition." For Elena, "The way she kind of behaves at times . . . I feel a little . . . [like] an outsider." This is the sister who had told her both, "'Don't call my house after 10 o'clock'" and, after her mother had gone to the emergency room, "'Well, you should've called my house.'" "She's like the most successful one out of all of us . . . married for like 30 years to the same

individual" with "perfect children" and, Elena believes, has a perspective that her life "will not

be disrupted" by her mother's care needs. Elena's struggle is that "I have a hard time

understanding . . . my sister's behavior and I wish my mother could do a better job of, I don't

know, explaining it," intervening, and boundary setting. Asked if the challenge was with more

than one sibling or just the next older sister, Elena said. "for the longest [time] it seemed as if it

was everyone just following her lead" and "whenever there's been a discussion or . . . any

differences . . . my other sister is quick to defend" the next older sister. More recently, she felt

that the oldest sister had "been more understanding." Elena saw it "more as . . . just an issue of"

the next older sister.

   Setting boundaries. Although disappointed that her mother was not able to set boundaries

with her sister, Elena described "one of the first times" she herself "actually . . . put up

boundaries" with her sister. Related to plans for the sister's son's wedding out of the country,

her sister asked Elena, "'Do you want to make Mom's arrangements . . . to travel to the

wedding?'" Elena replied, "Well, it's your son's wedding, so I think you need to be the one to

make the arrangements for Mom" and, "You know, I'm not gonna be able to do that."

   Team. Elena's caregiving team was "who I can trust and who I can rely on"; "who you

can really trust"; and "who is reliable." Building her family team required "modifying

expectations" and realizing "who's pretty much all talk" and not reliable. Elena could not rely

on her next older sister who reneged on her suggestion their mother live with her while Elena

went to the fellowship. Elena realized her sister "wasn't always present as a CG" and "we never

really expected her to do a lot of caregiving anyway." By contrast, with her brother

"cooperation, has been just really, really helpful now," "cooperation, um, seems pretty good,"

and caregiving is "more of a shared thing." While Elena and her brother are 10 years apart,

having him on the caregiving team has "help[ed] me to understand him better."

 Self-care. Elena stated regarding unmet needs, "I don't think so. I mean . . . as a result of being a CG, no. I would have to say no." She shared two means of self-care. When coresident with her mother, Elena watched a comedy show in which the main character was "becoming a CG for" a parent "who was essentially pretty independent." Besides the humor, "there were just certain episodes [with] . . . life lessons to be learned." Regarding caregiving "dynamics" in the show, Elena thought, "Oh, I see those challenges. I experience those now." She also engaged in self-care during her fellowship, when she had "a chance to be away from everything and everyone and . . . to be alone and to just kind of reflect on my life." That led to realizing "we are the sum of our choices and our decisions and I am where I am because of the choices and decisions that I've made throughout my life," which countered her previous self-doubts. "I kept thinking . . . why am I here? . . . I never expected that . . . in my forties I'd be living with my parent. . . . This isn't how I envisioned my life." She then accepted "where I'm at right now."

 Loss. Her father's death was Elena's only stated loss. Role reversal was an inherent loss.

 Mom. The "bit of role reversal" was Elena's mother relying on her "emotionally" and "look[ing] to me for . . . the guiding hand." Elena wished unsuccessfully for her mother to "explain," intervene, and set boundaries with her next older sister. The interviewer asked, "Is it safe to say that your mother leans on you emotionally, but, at least related to your sister, you're not getting that same, um, emotional support back from her?" Elena replied, "Yeah, yeah." The role reversal appears to have caused a loss of maternal emotional support.

Coping with Caregiving

 Elena coped via learning, gratitude, acceptance, faith, and meaning-making.

 Learning. Elena learned from, authors, homilies, her own ponderings and past choices,

her mother, and her mother's dementia. From the dementia "I've learned a lot about patience and acceptance." Elena's mother's being "a good CG to" Elena's father "taught me patience, and . . . unconditional love and acceptance." Her choices in the past, having the "chance to be alone and to just kind of reflect on my life," and reading "enlightened me and helped me to realize . . . there were times when I could've made other decisions, but . . . this is . . . the path that I'm on because of decisions that I've made, and it is what it is." From an author she learned that "as we age . . . you can be happy if you change your expectations." Homilies taught Elena "you think you do the right thing," but "you can't control" others' reactions; "This is the journey that I am on . . . my cross to bear and . . . how we respond is . . . how . . . we will be judged . . . and I have to deal with it as best as I possibly can;" and "this is our testing ground . . . how we live our lives here will determine . . . the fate of our souls or whatever." She concluded, "So, . . . I'm doing the best I can."

Gratitude. Elena expressed gratitude for opportunities. The fellowship "gave me a chance to be alone and to just kind of reflect on my life." After the fellowship, a short-term job in "an agency" was an opportunity to see how "people make pretty bad decisions and it affects children in their lives really badly", which made Elena thankful "for the life that I had lived" and "the privileges . . . that I've been given in life." One of the privileges was "my childhood was extremely ordinary, which is perfect. . . . You don't recognize the value of an ordinary life" without "any trauma." "I had everything that I needed . . . it was just good." Even her mother's Alzheimer's diagnosis was a source of gratitude because it "provided me with, um, relief."

Receiving gratitude. Elena's mother was also grateful to Elena. For "the diagnosis of Alzheimer's," she told Elena "Thank you . . . for making me aware what's going on." Following her emergency room visit, she told Elena, "Had it not been for . . . you Elena . . . taking care of

things that day, even though you were far away, who knows what would've happened."

A bit of acceptance. Elena realized the need to accept that when "do[ing] the right thing," "you can't control" "the reaction you get" and applied that to her siblings and her cousin. She worked to "accept . . . where I'm at right now because . . . of decisions I've made." Though "I reflect upon . . . where I might've made a decision differently," Elena was no longer saying, "This isn't how I envisioned my life.'" She conceded, "There is a bit of acceptance."

Faith, philosophical, and meaning-making. Elena's response to the question of how caregiving has affected her spiritually and emotionally was to quote T. S. Eliot (1942), "We shall not cease from exploration; And the end of all our exploring; Will be to arrive where we started; And know the place for the first time" (Section V, para. 2). From an author on the radio, she applied a "very important happiness skill [of]. . . having reasonable expectations" (NPR, 2019, para. 29) to "how I envisioned my life."

Elena, who self-described as Catholic, learned from a priest's homily that "the journey that I am on . . . is my cross to bear and I don't mean it in a negative sense" and "How we respond is . . . how . . . we will be judged I guess by our maker as I see it." Another priest stated, "This is our purgatory . . . with a little *p* and this is our testing ground . . . and how . . . we live our lives here will determine . . . the fate of our souls or whatever." Elena stated, "So I saw it as . . . spiritually this is what God has given me to deal with, and I have to deal with it as best as I possibly can." These thoughts led her to say, "So, . . . I'm doing the best I can."

Elena was doing her best by living out values she learned professionally. "When I first started working in aging, I was amazed . . . how it's written into statute [that] . . . the elderly or– or people in nursing homes and–and assisted living facilities are supposed to be treated with dignity, courtesy, and respect." Elena recognized people "don't always think that way as a

society." Caregiving gave her a chance to live her ideals, "This experience . . . as a CG has just kind of helped to . . . value the importance of treating elders with dignity, courtesy, and respect."

<center>**Patterns, Relationships, and Themes**</center>

The preceding discussions present how the participants describe their caregiving experiences. The remaining research questions are addressed below. Each CG-CR dyad is represented by the first letter of the CG's pseudonym (e.g., Ann = A, etc.).

Interface of the Caregiving Phenomenon

How the caregiving phenomenon interfaces with the societal, caregiving, and family systems, the relationships with the CRs, and the CGs' sense of identity is discussed in the following sections.

Interface with the societal system. These CGs spoke little of interfacing with the societal system, a consequence of living in "a very small, small world" (S) that "has shrunk quite a bit" (S). CR behaviors, not knowing "how she's gonna interpret things . . . what she's gonna say" (S); having "no filters anymore" (P); and having "every little infraction we have in our lives gets reported out to the world" (P), lessened societal interactions. Such statements suggest that these CGs anticipated stigma and did not find the societal system to be "dementia friendly" (ASC, 2017, p. 39). Exceptions were neighbors (D), friends (D, S, P,, J), extended family (S, E), houses of worship (D, S, E), and the divine (A, D, S, P, E), which provided support to CG and CR, even "bless[ing] my heart tremendously just to see how many reach out and care for her" (S). Two CGs (D, E) were employed. E was no longer coresident with her mother because of career changes. D had chosen to stay minimally in her profession and was ending coresident caregiving due to her husband's move for a job and she planned to re-engage in her career.

Interface with the caregiving system. These six dyads used few caregiving services,

reflecting the fragmentation of formal dementia caregiving in the US. (Feinberg & Levine, 2015). None described centralized or systematized services.

Day Programs. Four CRs (A, S, P, J) attended day programs part-time, usually at a local senior center. Two CGs expressed appreciation for these "very helpful" (A), "absolutely necessary and wonderful" (P) programs. One (A) was using a dementia specific program and one (J) had found a dementia specific program, but felt her mother was not yet at a stage where that was appropriate. Consequently, the latter (J) went with her mother to engage in regular senior center activities for people more mentally "active" and could not benefit from a caregiving break. For A, S, and P, day programs provided a break from the constancy of caregiving and opportunities to get together with friends, relax, and tend to their own needs.

Paid in-home care. S and D utilized paid in-home care from 4 to 20 hours a week. While helpful, S could not extend it to respite care because of her mother's medical needs. The service gave an opportunity for "time away" (D). Finances prevent J from hiring in-home care (J). P planned to hire in-home care but was unsure how to find someone intermittently.

Other aspects. Only one CG had attended a support group, but she had not gone "for quite a few months" (A). She did benefit from addressing feelings of guilt and from increased gratitude that her situation "could be a lot worse" (A). One CR lived in a "senior apartment" (E) but received no associated services. Only P's mother utilized a transportation service which was "wonderful" (P) for taking her to the senior center day program. P chose not to use that service for transportation to medical appointments because she wanted to be with her mother for those.

Medical care. CR medical appointments were time consuming (D, P, J, E). E initiated her mother being diagnosed, and J was planning to push for her mother to have a neurologist manage her mother's dementia medications. A physician did help E make a travel decision for

her mother after a medical procedure. No CG described integrated care with her mother's PCP.

Summary of the caregiving system. Not only were the PCPs not the recommended one-stop source of information and referrals (Sutcliffe et al., 2015), but no CG spoke of having any centralized information source. They sought out services themselves. Adding services required effort with uncertainty (P, J). S did not put forth the effort since "respite care . . . isn't really possible because . . . companies that you can hire can't do the insulin" (S). No CG complained about the caregiving system other than the slowness of public service provision (J).

Interface with family systems. This section first considers the mother-daughter caregiving dyadic relationships within the family system and then the CGs' families of origin.

Interface with the care recipient. These CGs primarily spoke positively of their mothers as CRs who were "pleasant" (A), "very sweet, patient" (D), and "easy to get along with" (D); "not demanding" (A) and "pretty compliant" (S); "good" (P) and "generous" (P); and relationally "better" (J), no longer faultfinding (J); and grateful (A, E). There were challenges with their mothers, including infrequent behaviors (A, S), "pretty self-centered" (D), "stubborn" (D), "trouble" (P), "more negative" (P), "less social" (D), and less interactive (J). Due to CRs' deficits, not knowing the CG as her daughter (A, S), and the role reversal of parental dementia caregiving (D, E), CGs found their mother to be less "emotionally available" or supportive (D, E), not a "helpful presence" (D), and not "able to connect" (S). Some CGs cared for their mothers on a foundation of a positive (A) or "pretty good" (S, E) relationship. In childhood, P and J received limited support and A could not "demand a lot from" their mothers. Two dyads (P, J) had complex, sometimes conflicted relationships, with differing degrees of healing.

Interface with the FoO. A's FoO was uniquely positive in her caregiving experience. For the other CGs, alcoholism (D, J), abuse (P), conflicted relationships (D, P, J, E), passive

abdication to the CG (S, E), and blended families (P, J, E) impacted caregiving.

 Negative impacts. D's brother's alcohol abuse was "incredibly hard . . . to manage and caused a lot of stress and upheaval" (D) and the stress related to her siblings "was the difficult part" (D). S did not have overt conflict with her brothers and stated they are "supportive" (S) of her caregiving. However, S had some FoO related stress in caregiving even without conflict as her brothers did not appear to help her make the decision to begin caregiving and she chose to emotionally protect them from the daily negatives. P felt hated and resented by two of her siblings for doing the right thing in caring for her mother and received little to no help from them. She had been able to heal her relationship with her mother, but efforts with her siblings had been unsuccessful. J's blended FoO with two parents abusing alcohol and a "very selfish" (J) mother was the foundation of a time of estrangement from her parents; unresolved and unanticipated conflict with her stepsiblings, exacerbated by her stepfather's death; and conflict and lack of support from her brother. E denied that caregiving changed her relationships with her siblings, but after her father's death, which coincided with the initiation of caregiving for her mother, she felt like "an outsider"(E) and "excluded by" (E) her next older sister who "treat[ed] . . . me differently. . . . [like] I'm not a full sibling" (E). These CGs' stories suggest it is possible to be in a loving caregiving relationship despite deep hurts in the past (P, J), that emotional and spiritual work are beneficial (P, J, E), that the FoO is relevant to caregiving for a parent (all), and that some issues and relationships may remain unresolved (D, P, J, E). Caregiving for a mother and conflict or, in the case of A, harmony in the FoO appear to be mutually influencing.

 Caregiving as exacerbator or revealer. Caregiving may influence FoO dynamics by exacerbating or revealing existing challenges. The statement that "life is very much intertwined and so . . . caregiving maybe exaggerates some of what is already happening in . . . my life but

not necessarily the cause of it" (S) was reflected in these CGs' stories. S's FoO's tendency to

"denial, and we don't communicate" (S) meant she made her mother's caregiving decisions

alone and carried the load without asking much of her brothers. D's FoO was "able to keep it all

together" (D) until her parents needed care and then existing "family issues started emerging"

(D). J learned through the caregiving experience that her stepsiblings were not close as she had

perceived, and E better understood the dynamics with her siblings that were "always there" (E).

 Opportunities. FoO related emotional pain that may be exacerbated or revealed by

maternal caregiving can be an opportunity for personal, relational, or even professional growth.

That is not to minimize the reality of the emotional pain expressed as "more depressed," "pain in

the neck," "incredibly hard" (D); "hate me," "resent me," "angst" (P); "pretty devastating,"

"awful" (J); and "a sucker punch," "a slap in the face," "a gut punch" (E). Yet J was able to say,

"my relationship with my mom is the best it's ever been." E learned "who I can trust and who I

can rely on" (E) and implemented boundary setting with her sister. She demonstrated that she

was putting effort into applying the concept of "the reaction you get is the reaction you get" (E)

to the choices of her family and her mother's inability or unwillingness to intervene with her

sister. D came to see that her years of caregiving "will inform . . . whatever work I have to do in

the future" (D). P was able to release her FoO conflicts sufficiently to focus on her love for her

mother. For several CGs (D, S, P, J, E) learning who they could rely on informed the formation

of a "psychological family" (Boss, 2011, p. 79) that included none or only part of their siblings.

For dementia CGs, a "psychological family" (Boss, 2011, p. 79) or "family team" (p. 79) is

composed of anyone who can "ease your load" (p. 79), "who's there for you, . . . who has your

back, . . . [is] unconditionally supportive, [and is] like a good sister or a good brother" (p. 79).

 J's caregiving story included a subtext of opportunity for relational healing and personal

growth. Her history included a childhood of caregiving followed by misplaced guilt, not being able to obtain her parents' approval, and expectations to be "perfect" (J). Her capacity to return to provide care for her mother, to reconcile with both of her parents, and to find the sweet aspects of the bittersweetness of caregiving is noteworthy. The second episode of caregiving was an opportunity for J to further free herself from the false messages of her childhood that were reinforced in a "conflicted" (J) adult relationship with her mother. She opened herself to healing in some relationships and to realities that diminished others. Saying "yes" (J) when her mother asked, "Will you come home?" (J), brought healing and reconciliation in her parental relationships. J accepted that she was not close to her stepsiblings, that her brother was little support, and the reality that she must take "care of" (J) problems.

The decision to care. The choice of these women as their mothers' primary CG was often shaped by FoO expectations and dynamics, including being "parentified" (J) as a child caregiver (P, J). These CGs were "the responsible one" (D, P), the "stable one" (D), the one who had been a CG as a child (P, J), whose mother or father expected them to be a CG (D, A), or whose sibling was not expected to be a CG (E). Gender appeared to play a role, although that observation is likely influenced by this study's focus on daughter CGs. Gender and position in the FoO had mixed influence on the choice of CG, complicated by blended family dynamics for P, J, and E. In the traditional FoOs the CGs were the oldest or only female (A, D, S). A believed that her mother "always thought I had to take responsibility anyway" (A) because "I'm the oldest" (A), whereas E experienced cultural expectations to care as the youngest female.

Which siblings were supportive to the CGs also varied. E's primary help came from her brother with little involvement of her sisters. P and J also received help only from a brother although it was minimal. A, who experienced harmony and teamwork amongst her siblings had

only sisters. D was little supported by both her sister and brother who were the "difficult part" (D) of caregiving. S, who had only brothers, became the caregiver by default with her brothers failing to step in when her mother first needed care.

The role of trust. E and A spoke of the importance of trust in caregiving teams. E learned from caregiving who of her siblings "I can rely on" (E) and "really trust" (E). About her brother she used the words "cooperation" (E) and "really, really helpful" (E) and added, "I know who I can trust and who I can rely on" (E). In A's story of a positive relationship with her sisters and their capacity to be an effective caregiving team, she emphasized trust. "We've been able to go and not be angry with one another and still really trust . . . yeah, we're very, very lucky" (A). E's connecting reliability and trustworthiness and A's example suggest that trust may be foundational to a functional caregiving team. Indeed, D, who declared her team had been herself and her husband, clearly found him to be trustworthy and reliable until he had to move for his job. Other than A and E, the CGs did not use the word *trust*, but for three (D, P, J) it was clear that they had little trust in their siblings on whom they could not rely for caregiving help and with whom they were not a team. P specifically stated she and her siblings "don't have each other to depend on" (P). Without FoO to rely on, these CGs found others they could trust, husbands (D, P), daughters (S, J), cousins (S, E), and friends (A, D, P). P expressed her trust in her friends, "When they come and stay with my mom, then I don't have to worry" (P).

Interface with caregiver identity. Orona (1990) noted that the "lack of reciprocal validation" (p. 1255) that is dementia care led to caregivers losing "remnants of their own identity" (p. 1255). Bowen (1992) deemed identity to be "equivalent" (p. 109) to DOS and these CGs clearly found maternal caregiving challenged their identities. P, J, and E referenced having done emotional work related to identity. Six years into caregiving, D was aware that solo

caregiving did not suit her, and she was "get[ting] more depressed" (D). CG depression was associated with caregiving alone and highly associated with loss of self (Nichols, 2001). D was striving to preserve her "own life story" (Hodgetts et al., 2003, p. 382) and her sense of self rather than be engulfed in the caregiving role (Skaff & Pearlin, 1992) as she contemplated ending coresident caregiving and refocusing on her professional identity. J, who had done therapy to deal with her childhood message, "Don't have any needs" (J), recognized her need, based on her identity as an "introvert" (J), for "alone time" (J) that "I don't ever get" (J). Caregiving was preventing her from meeting an identity-based need. S described her "very small, small world" (S) that "has shrunk quite a bit" (S), a possible threat to identity. Caregiving related activity constriction "may be mirrored in the loss or shrinkage of self" (Skaff & Pearlin, 1992, p. 656). S also struggled between the demands of her identity as a daughter/caregiver and a wife and mother. These ideas and the statement, "I feel like I don't have my own life" (P), suggest a potential for a diminished self or sense of self.

  Loss of mother as mother. The challenge of identity as daughter and CG was noted by these CGs. Three (A, S, J) of the four (A, S, P, J) CGs who had experienced child rearing paralleled that experience to caregiving. CGs spoke of the parent-child role reversal, "I'm the parent, she's the child" (D); "I've switched over from being . . . the child to the parent" (S), "bit of role reversal" (E); and of how dementia was taking away their mother, "I know I've lost my mother" (A), "not really the mother I once knew" (D), "I see her slipping away" (J), and wishing for maternal emotional support (E). As these CGs navigated care for a mother whom "I've lost" (S) and balance being "her child/mother" (Macaulay, 2014, para. 8), they experienced an altered identity in relation to their mothers, suggested by S's "distanc[ing] myself from her" (S) mother emotionally, "not thinking of her as my mom" (S). For S, the loss was reflected by her mother

not "really even look[ing] at me as her daughter anymore" (S). The person who likely named her

"might've called [Sarah] by name twice" (S) "in the year and a half that she's lived here (S). S

felt "loneliness" (S) and stated, "I miss her" (S). For J, even as her mother was "slipping away"

(J), they were "get[ting] along well" (J). Building on a historically conflicted relationship, J did

not express a loss of mother as mother. Neither did P express such loss. She and her mother had

long functioned with role reversal and her mother was cognitively still present.

 Reverse attachment. Two CGs described their mothers as being attached to them in ways

that mirror childhood attachment. J stated that her mother was "at that stage where she wants to

be with me all the time, every second" (J), "can't be left alone at all" (J), and "go[es] out front

looking for me" (J) if J is gone. "It's kind of like we're attached at the hip" (J). S said her

mother was "clearly attached to me . . . her primary CG" (S), "attached to me . . . more so than

anybody else" (S), and "very fixated on having me around" (S). S is the one her mother "come[s

to] for security" (S). In moments without S nearby, her mother was "untethered" (S). Of interest

is that only S's PBI score revealed "optimal parenting" (Parker et al., 1979, p. 2), suggesting that

she could go to her mother for security as a child. Loboprabhu, Molinari, and Lomax (2007),

noting that object relation theory has been little applied in dementia, suggested that dementia

CGs may function as a "'maternal object'" (p. 148) who provides "a 'holding environment' of

warmth and safety" (p. 148). Given that CGs for a mother are likely caring for their own original

"'maternal object'" (Loboprabhu et al., 2007, p. 148), this role reversal may merit additional

research.

 Loss of freedom. Prior to caregiving, these women defined themselves as mothers, wives,

daughters, sisters, friends, retirees, employees, counselor, educator, minister, and public health

professional, among others. None suggested they had lost these other social identities, but loss

of freedom to engage in life in noncaregiving ways emerged from the constancy of caregiving.

Caregiving disrupted previous self-directed lifestyles and spontaneity; socializing, visiting, and

receiving visitors; retirement, career, and life plans; and self-care and time alone. The result was

challenges to their identities as autonomous selves, friends, parents, social selves, professionals,

employees, and an "introvert" (J). Their words best summarize the challenge of going from

being content with "the route that I was going six years ago" (D) with "a really good rhythm and

. . . doing things we really like" (D) to "I feel like I don't have my own life" (P).

Summary. There is insufficient data and focus in this study to deeply examine mother

loss and the impact on personal identity for CGs whose mothers are "here but not here" (Boss,

2016, p. 270). Because of the significance of the mother role in identity formation, the

association of CG loss of self to depression (Nichols, 2001), and the potential demonstrated in

the current study for attachment reversal in parent care, offspring CG identity offers an area in

need of further research (Shifren, 2017). This data does demonstrate that caregiving identity

challenges may be difficult and require remedy (D, J) and can be an opportunity to engage in

identity work or consolidate previous work (P, J).

Making Sense of Caregiving

The question of how these CGs make sense of their experience is expounded here,

beginning with their initial responses. Their immediate answers to what gives their lives

meaning in caregiving were, "I am where I'm supposed to be" (A); "I wish I could say every day

I can find meaning, but that's not true" (D); "this has got to be the best place. This has got to be

good for my mom" (S); "Oh, well, I love her, you know? I love her, and . . . it pleases me to

know that she's taken care of and that she's well and that she's healthy" (P); "Giving her the best

quality of life that she can have" (J); and "this experience . . . as a caregiver helped to . . . value

the importance of treating elders with dignity, courtesy, and respect" (E). The varied responses

suggest that finding meaning is idiosyncratic, but there were common themes discussed in the

following sections. An unexpected theme was the role of dialectics which framed participant

perspectives on positivity, challenges, and opportunity.

Adding meaning. Despite leaving homes and jobs to begin coresident caregiving, D and

her husband intentionally "found things that . . . added meaning to our lives" (D), furthering his

education and staying minimally engaged in her career. Other CGs added meaning via learning.

Via learning. For A, learning from difficult experiences that are "here to teach us" (A),

such as dementia caregiving, added meaning to those experiences. E "learned a lot about

patience and acceptance" (E) from her mother's caregiving example and from the dementia

itself. She also became more "enlightened" (E) about her own life's path from reading and self-

reflection, learned to alter her expectations of others from an author and a priest, and placed her

caregiving experience into an eternal perspective based on learning from a homily. J self-

educated related to her mother's care, but she reached a point that she felt "overwhelmed with

information" (J) whereas A found it helpful to "always try to learn more about the disease" (A).

Gratitude and positivity. These CGs all referenced the positive and good in their lives,

but some found it "really hard to . . . stay positive" (S) because "there's some good stuff too, but

. . . you don't really see the good stuff while you're in the midst of it. You see the challenges,

and . . . not really . . . the benefits" (S). Yet S and the other participants were appreciative of

others, including the caregiving team (A, E), husbands (D, P), a cousin's support and

understanding (S), spiritual supporters (D, S), friends (D, P, J), and God (S); and of opportunities

to see their mothers' enjoyment (S, P), "inform my" (D) future career endeavors (D), reconcile

with parents (J), live where they do (A, J), "reflect on my life" (E), and experience clarity and

relief from the Alzheimer's diagnosis (E). Looking to the past, E was "thankful for, for the life

that I had lived" (E) without childhood trauma and J for the "good skills" (J) she learned from a

difficult childhood. The CGs saw the value of thinking positively, "I just recently realized that I

need to start reading more positive things" (A) and found it took effort to "kick myself in the butt

. . . [to do] that whole thankfulness and gratitude" (D). For J, the positive outlook allowed her to

say, "I don't look at it as being a burden or something I don't want to do. I'm . . . glad to do it"

(J).

   Positive psychology. While these CGs verbalized gratitude, positive aspects of

caregiving, and putting effort into positivity, the three facets of happiness or well-being in PPT,

positive emotions/pleasure, meaning, and engagement in life (Seligman et al., 2003, 2006), are

only partially evident. They clearly engaged in finding meaning and shared some positive

emotional experiences, particularly humor. Their engagement in life was more limited,

evidenced by S's world being "very small" (S) and having "shrunk quite a bit" (S) due to

caregiving. These CGs did demonstrate that they were engaged in a PPT activity, putting

strengths to work in new ways (Seligman et al., 2005) when they talked of doing a good job,

being a "good daughter" (P), and "doing the best we can" (S, P). There were also dialectics in

their positivity, expressed by S, "some good stuff . . . challenges, and . . . [hard to see] benefits"

(S). That statement agrees with positive psychology as a "dual aspect theory" (Seligman, 2003,

p. 127) and hints at the finding of simultaneous burdens and gains in dementia caregiving (Lim

et al., 2011). Specific ways in which each CG provided examples of recognizing the positive

and making meaning are provided in Table 3.

   Accepting, adjusting, and adapting. Dementia caregiving required "day-to-day" (A)

"constant adjusting" (P) to CR declines (A), changing needs (P), and behaviors (S), parents'

aging (D), lack of assistance (D, P, J, E) and negative reactions (E) from family, and one's own

past decisions (E). For these CGs, acceptance entailed attitudes of "I don't have any grand

expectations at this point" (D), "hang[ing] on to" (S) realistic expectations (S, E), "trust[ing] God

with" (S) what remains after doing one's best, and realizing what "you can't control" (E). Then

having acknowledged "it is what it is" (P), doing "the best" (S, P) one is able.

  Doing the best we can. It comforted these CGs when, recognizing their own limitations

and that "there's not a perfect answer" (S) in dementia caregiving, they could say, "we're doing

the best we can" (S). This was so in simple statements like, "I'm doing a good job" (D) and "I'm

doing the best I can" (E), and in comparisons to other caregiving options. "She is much healthier

living with us than by herself" (P). Compared to being in a facility, "I can treat her probably the

best" (S). Others, such as P's husband or even the CR, confirmed the good work, "The way you

take care of her, she's gonna live to be 100" (P). A inferred her mother's satisfaction, because

she "would never want to live alone" (A) and "she does want to be here" (A). J's mother sought

her as CG, "I need you. Will you, will you come home?" (J). E's mother expressed gratitude to

her, "Thank you . . . for making me aware" (E) of the diagnosis and, "Had it not been for you . . .

who knows what would've happened" (E). Pride and a positive sense of self resulted from doing

their best. S was "fairly proud of the fact that . . . we can deal with what comes up, um, without

freaking out" (S). For P, "That part of me feels right" (P), "I feel like a good daughter" (P).

  Philosophical, faith, and spirituality. These CGs shared caregiving values, the role of

time in providing perspective, and the importance of spirituality and faith in caregiving.

  Values confirmed and challenged. Three CGs referenced caregiving related values.

Caregiving was a direct extension of A's belief "that we do need to take care of our parents" (A)

and, for S, meant "do[ing] our best to keep our word to . . . [not] put her in a home" (S). E had

learned professionally that older adults "are supposed to be treated with dignity, courtesy, and respect" (E) and being "a CG has just kind of helped to . . . value the importance of" (E) that mandate. Values were also challenged by dementia caregiving for S who "truly believe[s] that life has value" (S). Watching her mother living in a way that "is not how she wanted . . . her days to end" (S) and "not the kind of life that I want my . . . life to end" (S) caused "all those questions that come up" (S) along with "struggle with some of the" (S) related "challenges" (S).

      The role of time. Time provided a framework for caregiving for D who had been in the role for six years. Noting that "on a short-term basis this might have been better" (D), she could still look to the future and recognize "I will look back without any regrets" (D), "in the long run I think it will be" (D) sacred, and "this whole experience will inform my—whatever work I have to do in the future" (D). S and J were focused on the present day-to-day to "be as present for her" (J), "appreciate today" (S), and, "make the most of what you can" (S) since "I see her slipping away" (J), "we don't know what tomorrow brings" (S), "that's all we've got anyway is one day at a time" (S), and "we never know how long it's gonna be" (S). Still, those recognitions did not alter the sense that "on a day-to-day basis it gets old, it gets tiring" (S).

      Spirituality and faith. All these CGs referenced faith, spirituality, God or being blessed. A, S, D, and E spoke of attending a Christian faith community. Prayer (A, S), "connecting to God" (D), or asking of God (P) were also mentioned. J spoke of being "given a gift" (J) and being "blessed" (J) by the opportunity to reconcile with her parents. P also spoke of a gift, receiving "God's gift to me" (P) of wings of an owl, "my totem animal" (P). S stated she received from God both sustenance to "make it through the day" (S) and blessings through others in her faith community. J practiced mindfulness to deal with stress. P engaged in "meditating and doing deep body work and breath work and isolation tanks and meditation retreats and . . .

spiritual growth" (P). E's capacity to accept her circumstances and deal with caregiving and family stresses was impacted by priests' homilies she had heard. For P, past work and having "bonded" (P) "spiritually" (P) with her mother supported her "deep sense inside of me that . . . became . . . love . . . and peace and . . . a little more serene" (P) when her mother moved in.

  Realistic faith. D, who said her "relationship with God is very down-to-earth" (D), acknowledged without apology "bitching at God" (D) at times, not feeling like caregiving was "sacred" (D), and that, as a CG, "I'm no saint" (D). S experienced "spiritual . . . ups and downs" (S) and A had realized a need to engage more with her faith. E verbalized past struggles accepting where she was in life, but with self-reflection and spiritual teachings she came to acceptance of others' reactions and felt challenged to do "the best I can" (E) with the "cross to bear" (E), "testing ground" (E), or "purgatory" (E) of her life journey, believing her response is a basis of future judgment and eternal fate. These CGs' stories suggest spirituality and faith provide some support in caregiving, help to make sense of it, and are sometimes informed by it, but without being roseate in the messiness of dementia care.

  Dialectics. Marsha Linehan (2003), founder of dialectical behavior therapy (DBT), in her reasons for incorporating dialectics into therapy, emphasized the value of nondichotomous thinking and of "comfort with ambiguity and change which are viewed as inevitable aspects of life" (Linehan, 2003). From that perspective, the dialectics observed in these CGs' stories may have particular value for dealing with the challenging ambiguities and changes of dementia caregiving. Ambiguous loss is a hallmark of dementia caregiving (Boss, 1999, 2011). Orona (1990) found paradox in the experiences of dementia CGs. One CG outside this study stated of time with her mother with dementia, "Every minute is torture; every second is precious" (Macaulay, 2014, para. 2). These CGs described dialectics, "both at the same time" (P) and

"bittersweet" (J), and even named them, "dual truths" (S). They spoke of positive-negative polarities. Dialectics challenged these CGs to make sense of caregiving and gave them an opportunity to develop dichotomous thinking. For S, "dual truths" (S) included "this is hard, but this is good" (S) and "life is precious, but–but this is not the way my mom wanted to live" (S).

   Positive-negative. Statements that embodied the positive and negative simultaneously, included "things could be worse" (A); caregiving "doesn't feel sacred" (D) and "I'm sure it is" (D); "there's some good stuff too, but . . . while you're in the midst of it you see the challenges, and . . . you're not really seeing the benefits" (S); "it's all wonderful, and yes, it's all a burden," (P); "stressful and bittersweet" (J); and "a positive experience" (E) and "a bit of a challenge" (E). D was comfortable with her dialectic interactions with God that included "grousing" (D), "bitching, and whining" (D) while also seeking for "thankfulness and gratitude" (D). A observed ironies, if not full paradoxes, in her mother's condition. "She reads that but doesn't understand it" (A). "She does wanna help but she doesn't" (A). A's mother, who was a CG and lived in service of others from her own childhood, was like "about a two- or three-year-old" (A) whom "I wouldn't trust . . . at the stove" (A). In the care of her adult daughters, she did not remember her own adulthood. "Everything that she remembers is before she was 12 years old." (A)

   Thoughts and emotions in swing. Following discussion of the constancy of caregiving, A's words swung through the dialectics of the difficult, to the positive, to recognizing it could be worse, to hard loss and disappointment, and to the effort of coping; and from acceptance and adjustment to fatigue, to okay, and to coping via deep breathing. J's description prior to this time of caregiving evidenced bitter and sweet, from "devastating" (J) and "upset" (J), to "oh, well" (J) to "really terrible" (J) and "awful" (J) and to reconciliation, which was the sweet part.

   Challenges. Dialectical challenges were related to the CR mothers and to caregiving.

Mothers. The things these mothers cannot do represent the restrictions of dementia, whereas what they can still do reflected some sense of hope and possibility. However, while *can* and *can't* are apparent polarities that are simultaneously true of these CRs, acknowledgment of dementia progression, "I know that's gonna get worse" (A), demonstrates dialectic truth. That is, the CR has some abilities and is inevitably going to lose them. These mothers, once competent adults, now cannot do many things and are dependent on the CGs, who are now the competent ones providing care. Yet at one time, for offspring CGs, the CR was their competent care provider. Additionally, because of the limitations of dementia caregiving, the CGs who, in terms of abilities, *can*, encounter difficult *can't*s. "I can't even just sit in bed and read a book" (A) or "just run out to the grocery store" (A). A deeper aspect of the CRs' simultaneous abilities and inabilities is the dialectic of their being "here but not here" (Boss, 2016, p. 270), the definition of ambiguous loss (Boss, 2016). S felt lonely "not being able to connect" (S) to her mother, leading her to "distance myself from her . . . it's almost better . . . if I'm not thinking of her as my mom" (S). To do otherwise meant "it's a little more acute and . . . a little more sad" (S).

Dementia, known to alter personalities (Khan, Kalaria, Corbett, & Ballard, 2016; McKhann et al., 2011), brought dialectics to some of these mother-daughter relationships. P's mother, a "really positive person" (P), became "more negative" (P), complicating a relationship that had moved from "hate and angst and frustration and hurt" (P) to healing. At the time of the interview "under it all is the love" (P) with "a lot on top of it" (P) from the past and occasional resentment, anger, self-pitying, or other negativity possibly related to the personality changes that can happen in vascular dementia (Khan et al., 2016). P described the dialectic in her mother as being "good" (P) and "trouble" (P). By contrast, J's long conflicted relationship with her mother was "the best it's ever been" (J) due to Alzheimer's related personality changes. This

was simultaneously positive and negative, causing J some guilt, but "that's the truth though" (J).

Caregiving. There was a lack of positive spontaneity due to caregiving described by A. At the same time, "I'm prepared for whatever . . . she might be into" (A) and "on guard" (A). She needed to plan ahead for basic tasks yet was unable to truly plan because, with the inconsistencies of dementia, "we don't know what tomorrow is gonna bring" (A). D recognized that at one time caregiving "was fine" (D), but there were "moments where it is not" (D) fine. For her, solo caregiving was not fine, her reason for planning to end coresident caregiving. For S and J, their own limitations in effectiveness of caregiving reflected dialectics. S "can keep her [mother] safe, and I can keep her fed, and I can keep her clean" (S) and "I really can't meet all of her needs" (S). J "can't do everything, because it's just, it's too overwhelming" (J).

Caregiving guilt was experienced dialectically. J felt "guilt ridden . . . because I feel like I'm not doing enough for her" (J) while wanting to "give her the greatest quality of life that she can have" (J), but not "at the expense of myself" (J). Thus, for J, caregiving required finding a balance of self-care and other-care and holding the related and sometimes conflicting truths simultaneously. S could "kind of talk myself down from the guilt usually, but it doesn't make it go away" (S), both countering and living with the guilt. Her guilt was about "pull[ing] her away from her . . . familiar . . . surroundings" (S), despite being "the one that can take care of her" (S), having "to be here" (S), and "think[ing] this is best for her" (S).

Opportunity. Dealing with dialectics gave some CGs an opportunity for personal growth. P expressed a contrast that perhaps is not a true dialectic, but that was self-defining, She compared herself to her siblings, "I stand up and I do the right thing" (P), "but they also don't do the right thing" (P), concluding, "That's who I [am]. I have to do the right thing" (P). D stated both "that's not true" (D) that she finds daily meaning in caregiving and "I think I can look back

someday and say, 'I'm glad I was able to'" (D), supporting her processing the decision to end

coresident caregiving. S acknowledged it was a "struggle" (S) and a "challenge" (S) when her

long held belief that "life has value" (S) encountered her knowledge that living with dementia "is

not how she wanted things to play out" (S). The cognitive flexibility needed to hold both beliefs

is reflected in her statement that "there's not a perfect answer for this kind of a disease" (S). For

E, caregiving provided dialectic opportunities to better understand and be aware of her FoO

dynamics related to sibling relationships; whom she could rely on and trust; and largely

unspoken dialectics in her "extremely ordinary childhood" (E) without personal trauma "in a

household where everyone [else] had experienced like trauma at an early age or whatever" (E).

Even E's response to whether caregiving had made her more aware of sibling dynamics was

dialectic, "Yeah. No, yes. The answer is yes" (E).

Application of Bowenian Family Systems Theory

This discussion is placed here because it brings together preceding discussions of family

systems, dialectics, and CG identity. Bowenian family systems theory as a framework for

understanding offspring dementia CG experiences remained apropos for these CGs. They

evidenced Bowenian interdependence in that the changes in the mother CRs and related stress

evoked reciprocal changes in the CGs, such as feelings of isolation, being overwhelmed, and loss

of control (BCFS, 2016h), referenced as lack of autonomy in this analysis. These CGs did, as

stated in Chapter One, navigate the caregiving role within a family systems context. They also

experienced challenges to identity, which Bowen (1992) deemed "equivalent" (p. 109) to DOS.

Still, they verbalized coping with and adapting to caregiving stress, a sign of differentiation

(Murdock & Gore, 2004; Smith, 2013).

The Bowenian concept of DOS reflects the dialectic theme of this analysis. Dialectics

are seen in Bowen's emphasis on balance between autonomy and connection (Kerr & Bowen, 1988) and in the definition of DOS as "ability to be both a part of and apart from significant relationships" (Foose & Cicio, 2018, para. 6). For these CGs, both their autonomy and connection to the CR were challenged. The latter, for dementia CGs, is further complicated by the ambiguous loss (Boss, 2016) of the CR. That is, CGs must negotiate their DOS while being part and not part of a relationship with someone who is "here but not here" (Boss, 2016, p. 270). It is logical, then, that these GCs expressed a lack of thriving, discussed in the next section; but, even as their identities and DOS were challenged by the constancy of caregiving, they exhibited sufficient differentiation to care about their mothers' well-being (Kerr & Bowen, 1988).

The other seven Bowenian concepts were also evident in these CGs' experiences. While triangulation is a means of dealing with stress by dispersal without resolving the underlying problem (BCFS, 2016i), it can be argued that in dementia caregiving, the underlying problem will not be resolved. Thus, the caregiving team may form a functional triangle (Titelman, 1998) as evidenced by A. All six CGs tried to bring at least one other person into a caregiving triangle with them and their mother. Being alone in caregiving without a triangle was unsustainable for D. Trust was key for A's and E's caregiving triangles to function well. For E, the caregiving triangle improved her relationship with her brother. With regard to the nuclear family emotional system, these CGs clearly evidenced antecedents in their FoOs that contributed to their caregiving frustrations (Keeling et al., 2008). Expectations to be responsible (A, D, P, J, E), to take blame (P), and to have no personal needs (J) were evidence of family projection processes that were borne out in the role of CG. Multigenerational transmission process positively influenced E's perception of caregiving. For S and A the past generations affected their caregiving and the next generations were being affected by their caregiving, altering

interconnectedness with children and grandchildren (Välimäki et al., 2012).

Siblings were prominent in these CGs' stories. For D, P, J, and E emotional cutoff, exacerbated by caregiving, was primarily with siblings, although J reconciled from a complete cutoff from her parents. For A and J caregiving was a bridge to prevent or overcome emotional cutoff (Jacobs, 2015; Wuest et al., 2010). S's purposeful emotional distancing from her mother could be framed as emotional cutoff or part of the grief process. After attempts to include siblings in care, D, P, and J appeared to cope better with caregiving by cutting off their siblings. Sibling position varied, with the three CGs not from a blended family (A, D, S) being the oldest or oldest sister. Cultural expectation of caregiving (Pharr et al., 2014) influenced the expectation that E, the youngest, would be the CG. Sibling rivalries and wanting to prove oneself the better offspring (Peisah et al., 2006; Williams et al., 2016) were also evident for P and E.

Lastly, the societal emotional process was demonstrated in barriers, isolation, and cutoff, with no caregiver verbalizing a strong positive connection to the societal or caregiving systems. See Table 3 for specific examples of the application of Bowen's eight concepts to these CGs.

Mental Health Needs

D's statement that "my wings have been clipped" was discussed related to loss of freedom. Its value as an analogy for caregiving fits well with the description of birds with clipped wings provided to the researcher by an amateur birder, "They're okay, but they can't fly" (Anonymous, personal communication, January 2019). These CGs reflected a state of being okay, but not thriving. D stated, "It's not a horrible, um, life," but "I really do not like" solo caregiving and "I don't have any grand expectations at this point." These statements by D show she was not thriving or finding much meaning in caregiving and parallel her elevated PHQ-8 and total and personal strain ZBI scores, and her low FMTC score.

Challenges. These CGs' dementia caregiving challenges suggest the need for coping with the inevitable disease progression, opportunities to rejuvenate and rest, breaks from the repetition and constancy, a sense of autonomy in their day-to-day lives, harmony, and hope.

Disease progression. With dementia, "know[ing] that's gonna get worse" (A) and "things are gonna get worse. You're gonna lose another ability . . . another memory" (S) describe continuous losses and a workload that becomes "a lot more intense" (S) and takes "a lot more time" (S). Simultaneously, "there's nothing you can do about" (S) CR declines. With "not much to look forward to with dementia" (S), "some days I'm like, you know just tired" (S).

Depleted. "When you're so depleted and the needs are so overwhelming" (S), especially when getting insufficient or disrupted sleep (A, S, J), P's words are apropos, "I get frustrated and I get exhausted and I wish everyone wasn't so needy" (P). Indeed, it is more than the demands of caregiving that depletes these CGs. "The rest of my job is . . . trying to take care of my family" (S) and when "Everyone's on me at the same time. Then I get very upset" (P). Other words used by these CGs that suggest being depleted include "I am beat. I am exhausted" (S), "It's exhausting" (P), "draining" (P), "angry and overwhelmed and exhausted" (P). Even with self-encouragers, "some days it's not enough for me emotionally to remember . . . those things. Some days I'm like, you know just tired, . . . just weary, and discouraged, and missing her" (S). When her mother's inability to communicate her needs meant S could not "do anything for her" (S), she found herself "sitting in my closet crying" (S). Thus, the demands of caregiving and of other aspects of life; the declines of dementia; the sense of loss as "she's been able to do less and less" (J) and "I see her slipping away" (J); and the inability to "do everything" (J), "meet all her needs"(S), or "do anything for her" (S) converged to overwhelm and deplete these CGs. That sense of depletion showed in elevated personal strain ZBI scores for A, S, D, and P.

Groundhog Day. A, D, S, and J found an aspect of dementia caregiving "overwhelming . . . that day-to-day repetitive" (S). This, too, was something about which "there's nothing you can do" (S). "There's a lot of repetitiveness in caregiving" (S) in the daily routines and in the CRs' behaviors and verbalizations. The words the CGs used to describe their mothers' repetitiveness revealed frustration, "a lot . . . a lot . . . over . . . over . . . again . . . again . . . again" (A); "repeat, repeat, repeat, repeat, repeat" (D), "explain this . . . 10 times" (D), "she will have eaten whatever it is 20,000 times and she'll look at me and say, 'What is this?'" (D), "the same conversation every day" (S), "It feels like it's Groundhog Day. Yeah. A lot—a lot." (J), "we have . . . a discussion about the food again" (J), "she'll . . . show me each [necklace] . . . like I've never seen it before" (J), "repeating, repeating, repeating" (J), and "I've heard that 30 times today" (J). In addition to the behavioral and verbal repetition, some CGs dealt with the CR not being able to "deviate in–in any way from . . . routines, um, 'cause it just throws her" (D). Particularly for someone who "get[s] easily bored" (D) or is emotionally triggered by the repetition (J), Groundhog Day routines and conversations are bothersome. As S stated, "It's hard to have a positive outlook all the time when . . . every day is gonna be the same" (S).

Loss of freedom. The loss of freedom has been discussed related to caregiver identity, but, considering the sense that it "feel[s] like I don't have my own life" (P), loss of freedom merits attention here as it pertains to mental health needs. These CGs had been content with a "really good rhythm" (D) they had before caregiving. Caregiving brought loss of freedom to structure their own lives related to forms of relaxation (A, D, S, P, J), household activities (A, S, P), personal care such as showers and sleep (A, J), and meals (A, D). The previous meal routine was "not . . . what my mom would do" (A) and "our menu planning has been . . . curtailed" (D) because she "likes the same things all the time" (D). Clearly these CGs felt a loss of autonomy.

A source of the loss of freedom was the constancy of dementia caregiving, expressed as "she has to be with you at all times" (A), "she wants to be with me all the time, every second" (J), "like we're attached at the hip" (J), and "I've always got to be focused on my mom" (S). That is so even at night (A, J) or when trying to rest during the day (J). When apart, "she come[s] looking for me" (A) and "she wants to go out front looking for me" (J). As dementia progresses, the CR "can't be left alone at all" (J), increasing the constancy. P had been able to leave her mother alone, but at the cost of the "constant burden" (P), "angst" (P), worry, and inability to "fully relax" (P) "the whole time I'm out" (P). Realizing her mother could no longer be left alone required changes, part of the "constant adjusting" (P). P expressed a common feeling about "more freedom" (P), "I need it. I need it. Yeah. I, uh, I really need it" (P).

Family conflict. A's experience of harmony in her FoO and her caregiving team along with the related strong sense of gratitude contrasted with the FoO conflict in other CGs (D, P, J, E). Their experiences were "incredibly hard . . . to manage" (D) and a source "of stress and upheaval" (D). Lack of caregiving help from siblings appeared to exacerbate the sense of being overwhelmed by caregiving. The significance of the struggle with family conflict previously discussed under *Interface with the FoO* bears repeating here: "more depressed" (D), "pain in the neck" (D), "incredibly hard" (D), "hate me" (P), "resent me" (P), "angst" (P), "pretty devastating" (J), "awful" (J), "a sucker punch" (E), "a slap in the face" (E), and "a gut punch" (E). These words and the statement that family conflict "was the difficult part" (D) suggest that minimization of the impact of FoO conflict is a need of these CGs. The role of trust in the FoO and the opportunities to better understand and to process FoO related issues suggest that deeper work than minimizing the impact of conflict may result from caregiving. Family conflict may not readily resolve, but CGs can learn "who I can trust and who I can rely on" (E) and can find

ways to build a caregiving team out of a "psychological family" (Boss, 2011, p. 79).

Hope. Lopez et al. (2012) asserted hopelessness could be altered by CG self-efficacy and beliefs in ultimate meaning. These CGs with their capacity to say, "I'm doing a good job" (D) and to engage in meaning-making should thus be equipped to counter hopelessness. Indeed, nothing in the interviews suggest the despair of hopelessness. Yet these CGs did not reference hope. They were able to speak of positives and of the future, but rarely together. The future entailed planning for their mothers' declines for all six CGs. For J, the future engendered uncertainty and anxiety. Only D, who was approaching an end to coresident caregiving spoke positively about the future, "I will look back without any regrets" (D) and caregiving "will inform my . . . work I have to do in the future" (D). This may be relevant to her framing her experience around time or the fact she had been caregiving for so long.

If there is "not much to look forward to with dementia" (S) and dementia caregiving is "like when my daughter was little" (J) and "taking care of my children all over again" (A), but more challenging (J) and with reverse development (A), then it is logical hope was not mentioned in the interviews. These CGs realized that their situations "could be a lot worse" (A), only one (J) referenced financial limitations, most had at least some formal or informal help, and none were dealing with severe behaviors. Almost universal low RMBC scores demonstrated the latter. Yet the realities of dementia care appear to have challenged at least their awareness of hope, leaving the question of the role of hope for CGs dealing with severe behaviors.

Summary. None of these CGs presented as having urgent or intense mental health needs. They could all name positives in their lives and were making efforts to cope with and process their experiences. In other words, they were *OK* but not thriving, like a bird with clipped wings. To oversimplify, the primary mental health need arising from this research would be the capacity

to fly or thrive. Each individual would need to define what flying and thriving means for them, but this study provides some general clues. Dialectically, the CGs have a mental health need to thrive and to some degree caregiving limits their capacity to thrive. As stated in Chapter One, optimally CGs seek out a middle ground on which they can retain personal autonomy and yet, often sacrificially, meet the needs of the CR (Hodgetts et al., 2003). In that vein, one identifiable mental health need that could move CGs closer to thriving would be cognitive flexibility, vis-à-vis dialectics. Other identified needs are enhancement of hope, harmony or at least relief from conflict in the family, respite as they define it, and autonomy.

Coping. In looking at these CGs' mental health needs, how they coped is relevant also.

Getting away. P referenced the value of getting away to cope with caregiving, whether on trips away from home or in the moment, "I run in the back and hide" (P). Other CGs (A, D, S, J) spoke more generally of a need for a break or respite, "I need some respite" (J) and "alone time" (J) and "the time away that I, I think I need" (D). Making the time away happen was a challenge for the five CGs (A, D, S, P, J) who spoke of needing it, as they "tr[ied] to figure out how to make that happen" (J). Doing so, though, "really did my heart and soul tremendous good" (P).

Making a change. Two CGs (D, J) expressed a need to make a change in order to cope. For J, the necessity of doing "something different" (J) meant finding a way "to relieve the stress" (J) so that she could continue caregiving, but not "at the expense of myself" (J). D had already made changes such as moving back to her own home from her mother's two years previously to continue caregiving. With circumstances making her a solo caregiver at the time of the interview, she had decided the change she needed to make was to end coresident caregiving.

Without blame. D, discussing the difficulty of coping with caregiving, explicitly stated, "it's not necessarily anybody's fault" (D). J asserted that her increased stress was not because of

her mother who was "not really different" (J), but rather her own internal need for respite. The

other CGs did not explicitly address fault, but none blamed their mothers for dementia related

behaviors or the situation. That was so even though two (P, E) had experienced being unjustly

blamed themselves, P as the one who carried much of the family blame in childhood and E who

felt "blamed for not communicating with" (E) her siblings when she had put effort into doing so.

Humor. Most of these CGs verbalized or demonstrated the use of humor to cope. Some

(A, P) were purposeful in their use of humor "to laugh it off" (A) or "make her laugh" (P). D, S,

P, and J exhibited humor throughout their interviews. Humor was found in caregiving itself (S),

related events (P), and even in the ironies of dementia (D, S). It was shared with the mother CRs

(P, J) and with the caregiving team (A) and used to counter frustration (J). P was philosophical

about the role of humor, "When you take care of your parents you have to develop a sense of

humor" (P) as an alternative to tears, "You can either cry about it, or you can laugh about it" (P).

Reframing. Reframing was not common amongst these CGs, but D, a professional in

counseling and counselor education, utilized reframes, along with finding rational narratives to

deal with family conflict and caregiving. One significant reframe, "not thinking of her as my

mom" (S), helped S be less sad and more emotionally supportive of her mother.

Trying and effort. Whatever means these CGs used to cope, there was evidence they did

so effortfully. For A, D, and S "stay[ing] positive" (S) or increasing positivity in their lives was

"really hard" (S) and required "working on" (A) it even to the point "I have to really like kick

myself in the butt" (D). CGs tried to "[deal] with" (D) family and with the CR (S, D, J). They

put effort into finding what was best for their mother's care (P, J). Even self-care (D), use of

humor (P), and obtaining additional services (P, J), meant to improve CG well-being, took effort.

While it is likely they all put effort into carrying an emotional load for their mothers, E and S

were explicit that they were "the guiding hand" (E) upon whom their mothers "relied . . .

emotionally" (E) or for whom they "carr[ied] . . . the emotions of the day" (S).

    Summary. Means of coping were more idiosyncratic than needs, suggesting that, even

when individuals undergo similar circumstances with comparable needs, what is beneficial will

vary. Humor was the most used means of coping and respite or a break was the most desired.

Discrepant Cases and Nonconfirming Data

    Answers to how these CGs' experiences are similar and how they differ are woven

throughout the preceding discussion and are further addressed here. E's caregiving interview

differed from the other participants in that she was no longer coresident with her mother. Also,

her mother's dementia diagnosis was new, whereas the other participants' mothers had either

been diagnosed or at least had symptoms for much longer. Both E's and P's mothers were less

cognitively impaired than the other CGs' mothers which was evident, for instance in their lack of

focus on repetition. A's situation differed by the strength of her team and lack of family conflict.

D and E were career focused and both were ending coresident caregiving.

Summary of Findings

    These caregivers' narratives did not demonstrate that they found the societal system

"dementia friendly" (AS Cymru, 2017, p. 39), though there were exceptions. None engaged in

fulltime work simultaneously with coresident caregiving. None of the CGs appeared to have a

centralized information source for services. Day programs and in-home caregivers predominated

with particular emphasis and value placed on the former. Medical care was burdensome related

to going to appointments with the CRs and no CG reported encountering integrated care.

Additionally, some had to initiate dementia diagnosing and management. Thus, these CGs were

largely navigating the caregiving system and to some degree the societal system in isolation.

This supports the notion that in the U.S. society does not meet the needs of dementia CGs, leaving them in a Bowenian societal emotional process of cutoff (BCFS, 2016g).

Family systems figured heavily in these CGs' experiences. One experienced positive FoO support and interaction, another received only verbal support from a distance, and the remaining CGs experienced FoO conflict and variations of limited support. The relationships with the mother CRs were overall positive, even for those with a historically conflicted maternal relationship. Caregiving did not appear to cause family conflict, but rather exacerbated or revealed existing issues, in the process giving the CGs opportunity to learn, grow, and heal relationships. It also revealed relationships and issues that could not readily be resolved. In turn, family conflict made caregiving harder for some CGs. Having a caregiving team was important for several CGs. Lack of a team, vis-à-vis solo caregiving, made for stressful caregiving. Team was defined idiosyncratically and reflects the construct of a "psychological family" (Boss, 2011, p. 79). The role of trust emerged as a factor in shaping the caregiving team.

In agreement with the stressful nature of solo caregiving, it has been associated with CG depression and with loss of self (Nichols, 2001). The constructs of role engulfment (Skaff & Pearlin, 1992) and "shrinkage of self" (Skaff & Pearlin, 1992, p. 656) and the risk of losing "remnants of their own identity" (Orona, 1990, p. 1255) in caregiving, were relevant to these CGs one of whom stated, "I feel like I don't have my own life" (P). Past therapy and choosing to disengage in coresident caregiving were protections for identity.

Loss figured in these CGs' experiences, notably, through role reversal, the loss of mother as mother. There were hints of a related concept of reverse attachment. Salient was the statement, "She's clearly attached to me . . . her primary caregiver, as the one . . . to come for security" (S). Loss of freedom to live their lives as they would like was also predominant.

There was variety in what the CGs stated gave meaning to caregiving, but they all engaged in making meaning via learning; gratitude and positivity; accepting, adapting, and "constant adjusting" (P); acknowledging their own good work and "doing the best" (S, E) they are able. Values, spirituality, and faith also gave meaning to caregiving. Values both informed caregiving and were challenged by it. Placing caregiving in the perspective of time, both what it might mean in the future and engaging in the present, added meaning for some CGs. Engaging in formal religious activities, praying, receiving gifts and blessings from God, and mindfulness and meditation were helpful to these CGs. They were honest about the struggles of caregiving and reflected their realities in expressions of faith. Their meaning-making echoed aspects of PPT (Seligman et al., 2003, 2006).

An unexpected finding was the role of dialectics in dementia caregiving. It is, however, logical that dialectics would emerge from an experience of ambiguous loss (Boss, 1999, 2011) and dealing with "ambiguity and change" (Linehan, 2003). The words of the CGs, "both at the same time" (P), "bittersweet" (J), and "dual truths" (S); their embrace of the positive and negative; and their verbal swings are evidence of their dialectic experiences. These dialectical experiences may give opportunities for personal growth and to develop dichotomous thinking.

Bowenian family systems theory remained an apt framework for these CGs' experiences. Dementia caregiving challenged their DOS via their identities, autonomy, and connections to their mothers, contributing to the lack of thriving. There was cutoff, triangulation that at times appeared beneficial, and FoO impacts by way of nuclear family emotional system, family projection processes, and multigenerational transmission. The latter evidenced extending to succeeding generations. Sibling position played a varying role for these CGs. The societal emotional processes exhibited degrees of cutoff and consequent isolation.

At its simplest, the mental health need highlighted by these CGs' stories was for thriving. They experienced inevitabilities of dementia progression and others' reactions, felt depleted and overwhelmed by competing demands, found the repetitiveness of dementia caregiving bothersome, lost autonomy and freedom from the constancy of dementia care, dealt with "incredibly hard" (D) FoO conflict, and omitted references to hope. These CGs did not appear to have severe mental health needs but were not thriving. "It's not a horrible, um, life" (D), and "I don't have my own life" (P) indicate significant though not acute need.

Thus, these CGs may benefit from enhancement of hope, relief from FoO conflict, respite, freedom, autonomy, and learning dichotomous thinking. Their means of coping, getting away, making a change, accepting without blame, humor, and reframing all entailed effort. The humor reflected in ironies shared by these CGs, is itself a form of dialectics. Their strong use of humor suggests it is helpful. Indeed, since dementia caregiving is inherently dialectic and humor, commonly understood to entail a measure of the absurd, helps "socially construct paradox" (Jarzabkowski & Lê, 2017, p. 433), it is a logical and helpful means of coping and finding meaning. One CG saw it as necessary in parent care and as an antidote to tears. All the CGs found a respite, a break, or getting away to be beneficial or expressed a need for a break.

CHAPTER FIVE: DISCUSSION

The mental health needs identified for these CGs were dealing with personal depletion and their mothers' repetitiveness, lack of personal autonomy, low awareness of hope, and an overall need to thrive. They described their caregiving experiences as depleting, at times bothersome, a potential threat to personal identity, exacerbating or revealing of FoO dynamics, an opportunity for growth, a source of loss, informed by meaning and challenged by meaning, more tolerable because of past biopsychosocial-spiritual work, and dialectical. The interface with the societal system was little discussed in part due to their shrunken worlds and possibly due to discomfort with stigma. The CGs did benefit from some services in the caregiving system but referenced no centralized source of information or support.

The family systems of these CGs were considered related to their mothers and FoOs. The discussions of their mothers were mostly positive, despite some CGs having histories of maternal conflict. The FoOs, which shaped the decisions to care, were more negative than positive in these caregiving experiences. Yet caregiving provided opportunities for growth in some instances. Caregiving exacerbated or revealed FoO dynamics, particularly regarding siblings, and the importance of trust in FoO relationships. The concepts of Bowenian family systems theory were evident in the CGs' stories.

The analysis found challenges to CG identities, including in the loss of their mothers as mothers. Finding meaning for these CGs was idiosyncratic and there were common themes of learning, gratitude and positivity, accepting and adapting, recognizing their own good work, and spiritual engagement. Dialectics stood out across CGs, reflecting ambiguous loss (Boss, 1999, 2011), the value of dichotomous thinking, the challenges of caregiving, and the dialectics resident in their mothers with dementia.

CG differences were degree of FoO support, one CG no longer being coresident, severity of dementia symptoms across CRs, and choices regarding continuing caregiving. Similarities are discussed extensively in Chapter Four. Among the similarities were those observed in all or nearly all participants, experiencing divine support; loss of freedom related to relaxation; needing a break and finding it hard to take one; minimal reference to the societal or caregiving systems and no reference to centralized resources; positive sentiments toward the CR; lack of positivity in the FoO; the relevance of meaning and values; formation of a caregiving team from a "psychological family" (Boss, 2011, p. 79) and the related role of trust; and loss of mother as mother.

Evidence of Quality

The following discussion is based on Yardley's (2000) criteria (see Table 1). Additional evidence is provided in Tables 2 (Table of Themes), 3 (Tables of Specific Themes), 4 (Chart of Journal Data), 5 (Raw Quantitative Data), 6 (Triangulation of Quantitative Data with Findings), and Appendix C (Caregivers' Journals). Use of quotes throughout the analysis assure the findings go back to the phenomenon of coresident offspring caregiving itself (Smith et al., 2009) and to the particular (Smith & Shinebourne, 2012).

Assurances of Validity

 This discussion of the validity of the current study utilizes the criteria in Table 1.

Grounding in the data and sensitivity to context. Valid qualitative work should be grounded in the data (Pistrang & Barker, 2012) and sensitive to context (Yardley, 2000). The interview guide utilized open-ended questions to prioritize participant voices. Prompts were rarely needed as the participants spoke openly and provided deep and detailed responses. Raw data were provided throughout the presentation of findings and data analysis via a plethora of

participant quotes, evidence of grounding in the data. Participant quotes were provided to

support conclusions, and interpretations are drawn directly from the data. The interpretations are

not meant to be construed as broad claims the data do not support (Smith et al., 2009).

The participant sample fit well with the intent of the study, with one exception related to

coresidence. Because this research was focused on mental health needs in dementia caregiving,

participants were chosen, based on the evidence in the literature, who were at greater risk of

CGB. Choosing to focus on higher CGB led to the intent to interview participants who were

European American, non-Hispanic, female, offspring, coresident primary CGs, who initiated

coresidence in the preceding year. This research was dementia focused and applied a family

systems lens, leading to the choice of participants caring for a CR with AD or a related dementia

and who have sibling(s) capable of providing care. In keeping with IPA's intent to have

homogeneous participants, only those caring for a same gender parent, in this case a mother,

were included. Only choosing same gender dyads was due to evidence of qualitative differences

in caregiving for a parent based on whether the dyad is same or different genders (Allen et al.,

2012). Homogeneity was not maintained to the degree originally intended due to the inability to

obtain participants with the original criteria. Thus, after dropping the criteria of European

American, non-Hispanic, and initiating coresidence in the preceding year, the participants

differed in how long they had been coresident, race, and ethnicity, but were homogenous in all

other criteria with the exception that E was no longer coresident at the time of the interview.

The researcher was sensitive to relevant sociocultural contexts, primarily by listening and

privileging the participants' voices and stories. An example is an exchange with E during the

interview. E was raised in a family that immigrated to the US from Central America. The

researcher shared that the literature shows regarding "stress level in caregiving . . . that race and

ethnicity seems to play a big part" and asked whether "there were cultural expectations that had impacted your caregiving experience"? Sensitivity, openness, and privileging E's voice in that interaction resulted in a different perspective, that "in Latin America[n] . . . culture, uh, the youngest, you know, usually it's the youngest girl" (E) is expected to be the CG. In lieu of a demographic survey, the researcher asked screening questions relevant to the participant criteria over the phone prior to the interviews.

Commitment and rigor. The interview guide was developed directly from the research questions and the literature review. The fit of the data to the research questions and the literature suggests that the interview guide was adequately designed to obtain relevant responses. Fit and homogeneity of the participants is discussed above in confirmation of coherence. In keeping with Yardley's (2000) criteria, artifacts are provided in the appendices and additional artifacts are available, in the form of an electronic audit trail journal, to supervising faculty. The dissertation chair provided feedback throughout the research process related to the rigor of the study. The final product of this research is presented with an open invitation for the reader to judge its completeness.

Triangulation. Member checking, the two journals returned, and the quantitative measures were used for triangulation. Priority was given to the interview data. Member checking was done by providing the finished portion of analysis specific to the CG to her for feedback. Each was asked "if in any way I have missed your meaning" (researcher via e-mail) and "whether I have accurately represented your experience" (researcher via e-mail). Two different CGs provided brief, confirming feedback. The quantitative measures were not consulted until after analysis was done. The journals were read once and set aside until after analysis. Raw data are provided to support triangulations (see Tables 4, 5, 6, and Appendix C).

There was at least one source of triangulation data for each participant. Member checking was only confirming. Jane responded, "I enjoyed reading your document. It is accurate and was a good reminder for me" and Elena, replied, "It looks good and accurate. Thank you." The journal responses were mostly confirming (see Appendix C and Table 4) for A and D. There was a small amount of data that added to but did not conflict with the analysis (see Table 4). A smaller amount of journal data were nonconfirming in ways that did not alter significant findings. In A's journal, she referenced being "sometimes angry" (A). That does not disconfirm the A analysis, but rather is something either not revealed by her in the interview or not picked up on by the researcher. Secondly, D's journal noted that she "had a good relationship with both brother and sister" (D). However, she was referring to before caregiving, so that statement is not disconfirming of her story of conflict in caregiving. D's quantitative data (see Tables 5 and 6) on the LSRS also suggests she had had better relationships with her siblings in childhood, as evidenced by subscale scores for childhood affect and cognitions. Those subscale scores are the primary reasons her overall LSRS score, while below the level described as the most negative sibling relationships, were higher than other CGs in this study with conflicted sibling relationships. Additionally, the LSRS only rates one sibling, and these CGs were asked to rate the one most involved in their mother's care. For D, since her brother was deceased, that would have been her less conflicted relationship, her sister. Thus, for D, the analysis did not observe her better childhood sibling relationships, but it did observe her relationship with her sister being better than with her brother. This apparent discrepancy then does not disconfirm the analysis.

The remaining quantitative data for A, D, S, P, and E, presented in Tables 5 and 6, is primarily confirming with three additional exceptions. S's conflict with her siblings was not

overt in the analysis, yet her LSRS score was below the level indicating a negative relationship. This could be due to geographic distance, her being the only sister, the passive way in which caregiving was thrust on her, or an unobserved finding. The score reflects a lack of closeness but does not fit with the observed lack of conflict in her sibling relationships. Additionally, D's and S's RMBC subscores, showing the bothersomeness for memory related behaviors in their mothers, were slightly below the mean (D) and far below the mean (S). That is surprising considering that the analysis observed both being bothered by their mother's repetitiveness. Because A was above the mean, it can be said that the statement in the analysis that the CGs "found the repetitiveness of dementia caregiving bothersome" is only partially supported.

Overall, little triangulation data was in conflict with the data analysis, and none disconfirms primary findings. More importantly, the researcher asserts that the voices of the participants are not obscured, in these limited instances of potentially conflicting, but not disconfirming data.

Coherence and transparency. By embedding direct quotes throughout the analysis, interpretations are connected directly to the data. The researcher provided a transparent discussion of her biases and expectations in Chapter Three. Below, under Personal Reflections, that discussion is revisited from the perspective of the completed research. The researcher maintained adherence to phenomenology by delving deeply into these CGs' experiences in order to first understand them herself and then provide an understanding to the reader. Evidence of interpretative work is provided in the appendices and the presentation of patterns, relationships, and themes. The final product represents the systematic inquiry and the headings throughout the analysis reflect that coherence. The researcher asserts that the process is made transparent in its description here and throughout this work.

Impact and importance. The presentation of these cases and the analysis of the data in Chapter Three, with significant direct quotes, plus the data in the appendices provide sufficient raw data to give import to the voices of the participants. This study adds to the knowledge base by providing rich descriptions of these CGs' unique experiences. The explication of these CGs' mental health needs, which are cognitive flexibility, enhancement of hope, relief from family conflict, a break from caregiving, and autonomy, adds perspective to the knowledge base and provides emphasis to the importance of the FoO for offspring CGs. Awareness of ambiguous mother loss in mother-daughter dementia caregiving and application of DBT skills to CGs are potential contributions to mental health treatment. This discussion provides evidence of impact and importance of this study, but it is the reader who will be the judge of the final product.

Personal Reflections

While the persons of the participants are paramount in IPA, the person of the researcher is relevant and cannot be ignored. Rather, in qualitative work, particularly IPA, the person of the researcher is not assumed to be neutral. In the double hermeneutic of IPA (Smith et al., 2009), the researcher engages as self to interpret and enrich the meanings of the participants (Pietkiewicz & Smith, 2014). Because the researcher is thus engaged, her reflections relevant to the study and its findings are discussed, as transparency in this area is necessary to assure quality in the research (Yardley, 2000).

Relevant experiences. In writing about Family Conflict related to Mental Health Needs in Chapter Four, I found myself unwilling to write "amelioration of the conflict" because in my own FoO, the conflict exacerbated by caregiving is not one I feel can be readily ameliorated nor am I currently willing to make an attempt in that direction. Instead I wrote "minimization of the impact of FoO conflict." I believe the latter phrase fits well with these CGs' experiences, but

transparency requires I reveal the relevance of my own bias and experience.

It is also of value to briefly describe what has changed in my own caregiving experience since I wrote about it in Chapter Three. My aunt is now 94 and on hospice in her assisted living facility. She sometimes feels "worn out," and her cognition varies, but she is usually alert and oriented. Her attitude and kind spirit remain inspirational. My father, 91, had a period of declines and has moved into the same assisted living facility where he is now thriving. I have found it increasingly difficult to connect with him although we do not have a specific diagnosis to explain cognitive changes. There have also been significant changes in my FoO that have taught me about whom I can trust and rely on and have complicated relating to my father. Lastly, I have moved across the country, introducing me to distance caregiving guilt. My recent experience of taking a break from writing this chapter to make changes in my father's and aunt's Medicare drug plans is a picture of how this research has been intertwined with my caregiving experience. It is also relevant that I have not even begun to experience the caregiving constancy of the coresident CGs who participated in this study.

Reactions to findings. There were findings that I anticipated, some unconsciously, and others that were unexpected.

I expected that. A reason for my interest in the topic was an expectation, confirmed in the literature review, that FoO dynamics may play a significant role in the caregiving experience and that, in potentially renewing unresolved issues, caregiving might provide an opportunity to address them. My response to P's question about my research after the formal interview provides an explanation of the expectation, which I attempted to bracket throughout the data analysis.

I do have preconceived notions, of course. . . . The whole idea that this family of origin—

you have always been the one who took care of things and here you are, your mother's

caregiver. I do believe that that's what tends to happen. Of course, it doesn't happen in

every family, but that we live out those roles that–that get established. . . . You already

had healed your relationship with your mother, but there's something really beautiful in

this that–that I think it's an opportunity for people to either resolve or come to a place

where they can accept what their family of origin is and was. (P: "Wow, mm-hmm"

[affirmative]). And I don't know that that always happens, but I do believe that it brings

all that back up again. Or it can.

Boss (2011) stated, "Just as dementia's loss is strange and confusing, so are the family

relationships that follow" (p. 85) which is what I expected and what the research reinforced.

Unconscious expectations. In working with older persons as a social worker, I often

observed that their worlds had shrunk, but I did not consciously think about that observation

related to the current research. Yet, when the finding of shrunken worlds for the CGs emerged, it

was not surprising. In the same way, the theme of *getting away* did not surprise me even though

I was not consciously anticipating its application in the moment. In my past work I advised

professional CGs of residents with dementia to walk away when frustrated.

The unexpected. Despite the intent to consider ambivalence in caregiving, I did not

expect to see the significant role of dialectics in these CGs' stories. I also did not anticipate the

intensity expressed related to the bothersomeness of these CRs' repetition or, for two CGs, the

bothersomeness of disrupted meal routines.

The research process. The reflection here considers my role in this process and any

possible effects I may have had on participants. As to my role in the research process, this was a

single researcher study. As such I conducted every step of the study. Regarding possible effects

on the participants, my training as a mental health counselor has taught me to be "aware of—and avoid imposing—[my] . . . own values, attitudes, beliefs, and behaviors" (ACA, 2014, p. 5). I strove to do that in these interviews. Only in E's interview did I see points at which I could have been imposing my belief that caregiving has the potential to open awareness about FoO. She had already said that caregiving did not change her relationships with her siblings. Here is that portion of the conversation:

N: You had said before you didn't feel like caregiving impacted your relationship[s with your siblings].

E: Uh-huh.

N: I thought I heard you say it did shape your knowledge or your sense of–of amongst your siblings who you can count on.

E: Yeah. No, that's true. That's absolutely true. Yes.

N: Okay.

E: That is true. Because, you know, but then I mean I guess it was always there kinda.

[E provides an example here]

N: So, let me reshape that question one more time. Do you think that this process of caregiving has made you just more aware of the dynamics with your siblings?

E: Yeah. No, yes. The answer is yes.

On the one hand E's equivocation and my pushing the question could be interpreted as imposing my expectations. However, I was basing the question on what I had just heard her say and I believe I was following her lead rather than trying to lead her. Otherwise, the participants' apparent comfort in discussing their experiences and the unexpected findings are evidence I minimized effects I may have had on them.

Limitations

        This study demonstrates the same conundrum noted in Chapter Two regarding the

development of the FMTC (Farran et al., 1991), i.e., that finding meaning is idiosyncratic while

making the assertion that there is a way to capture the experience across CGs. In the same way,

each CG in this study experienced caregiving uniquely, yet the researcher has attempted to

capture the phenomenon across CGs. The developers of the FMTC expressed that the items are

not considered comprehensive or fully representative (Farran et al., 1991). This researcher

likewise asserts that these findings are not comprehensive or fully representative. She does,

however, assert that they are meaningful and that the inherent dialectic is a necessary and

potentially beneficial aspect of qualitative work.

        Specific limitations are incomplete homogeneity due to difficulty obtaining participants,

receiving member checking responses from only two of six participants, and self-selection bias.

These CGs who chose to participate may have been less overwhelmed by caregiving and could

thus find time to participate versus CGs who did not volunteer. The criterion of coresidence was

not strictly adhered to in that E was no longer coresident with her mother. Additionally, the

choice not to distinguish stepchildren, unofficially adopted children, or other unique

circumstances in the participant criteria appears to have contributed to a lack of homogeneity, as

the participants who were from blended families shared noteworthy complexities in their family

dynamics. Certainly, there were complexities for participants from more traditional families, but

the lack of homogeneity in FoO structure is noted here as a potential limitation of the study.

Lastly, IPA recognizes and engages the perspective of the researcher even while privileging the

participant experiences. Inherent in the double hermeneutic is that participants are limited in

their own perceptions of their experiences and researchers are limited in their capacity to fully

apprehend those experiences. Thus, recognizing that quantitative work also entails researcher interpretation (Smith, 2003), as in all research, there are limitations in this researcher's capacity to know. In a third hermeneutic, there are also limitations in the reader's capacity to know. While not a weakness particular to the current study, this discussion of hermeneutics is an acknowledgment of its intrinsic limitations.

Summary of Quality in This Study

In agreement with Smith et al. (2009), the researcher invites readers to judge the quality of this research and, using Yardley's (2000) criteria, its rigor, impact, importance, and completeness. The researcher asserts there are no claims the data do not substantiate and that the procedures were followed as planned, with specific exceptions outlined here and in Chapter Four. Additionally, the participants remained the primary focus throughout the work. The researcher has attempted to provide transparent logic behind the process of this research. Lastly, awareness of the researcher and of her biases was also maintained and bracketed as appropriate. Related transparency has been provided above.

<div align="center">

Recommendations for Action

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That these CGs in the trenches, serving their mothers, their families, and societies have unmet needs for rejuvenation and rest, breaks from the repetition and constancy, a sense of autonomy in their day-to-day lives, harmony, and hope, while unserved by any centralized mechanism for resources, evidences the very personal costs of the fragmented caregiving system in the U.S. These findings are relevant to mental health providers, members of the professional caregiving system, policy developers, caregivers, and researchers.

Mental Health Applications

Those who provide mental health services to offspring dementia CGs would do well to

attend to identity development, loss of self, loss of mother as mother, meaning-making, hope, autonomy, and the need for flexibility related to identity (Shifren, 2017) and cognitions. It is also likely that these constructs are interrelated. For example, loss of mother as mother is intuitively intertwined with loss of self and identity development.

Therapeutic relevance. While FoO conflict is clearly problematic for most of these CGs, their stories suggest that family therapy with their siblings may not be desirable. This gives potential insight into the lack of compliance with the family therapy module of the NYUCI when it was applied to offspring CGs (Gaugler et al., 2013, 2015, 2016). Sensitivity to CG family dynamics must always be a consideration when suggesting family therapy. At the same time, working from a family systems perspective appears to be relevant to offspring CGs. For example, utilizing the successful NYUCI intervention, even when offspring CGs refuse the family therapy sessions, could still be conducted through a family systems lens.

Potential interventions. Themes from this research suggest that interventions that enhance meaning, such as acceptance and commitment therapy (Hayes, Luoma, Bond, Masuda, & Lillis, 2006), which also improves cognitive flexibility (Lloyd, Bond, & Flaxman, 2013) and has demonstrated efficacy with dementia CGs (Losada et al., 2015); PPT, which also addresses hope (Seligman et al., 2006); and humanistic therapies which also promote autonomy (Association for Humanistic Counseling, 2018) may be beneficial. Additionally, in light of the role of meaning in caregiving, therapists for dementia CGs should be open to "integration of spiritual and religious values in counseling" (ASERVIC, 2017, p. 9).

Family systems. Because offspring CGs are caring for an original attachment figure and the findings suggest a possible reverse attachment in dementia care, therapies that privilege attachment may be applicable to working with these CGs. Attachment-based emotionally

focused therapy, though developed to work with couples (Johnson, 2017), is applicable to

individuals (Brubacher, 2017; Johnson, 2017) and families (Johnson, 2017; Stavrianopoulos,

Faller, & Furrow, 2014). Utilization of the tenets of Bowenian family systems theory to frame

clients' caregiving experience appears to be apt. Caregiver family therapy incorporates many

Bowenian elements (Qualls & Williams, 2013) and has recent evidence of efficacy, particularly

for offspring CGs (Wickersham & Qualls, 2018).

 Dialectics. While these CGs demonstrated cognitive flexibility at times and even

awareness of "dual truths" (S), they would benefit from increased cognitive flexibility to deal

with the ambiguity and conflicting emotions and cognitions they experience. If cognitive

flexibility can reduce emotional exhaustion and strain (Lloyd et al., 2013) and bring benefits

related to caregiver identity (Shifren, 2017), it can surely help dementia caregivers. DBT teaches

cognitive flexibility with its focus on dialectics, but in its entirety is an extensive therapy with a

significant time commitment (Linehan, 2015). Stand-alone DBT skills training has shown

promise for improving a variety of mental health outcomes (Valentine, Bankoff, Poulin, Reidler,

& Pantalone, 2015) and specifically for dementia CGs in a nine-week group (Drossel, Fisher, &

Mercer, 2011). Because the outcomes of that group – increased problem-focused coping,

decreased fatigue, enhanced emotional well-being, and decreased depressed mood – can benefit

dementia CGs, those who treat these CGs may wish to consider DBT skills training.

 Opportunities. These CGs demonstrated that maternal caregiving, in addition to being

burdensome, may bring opportunities for personal growth as it increases awareness of FoO

dynamics and challenges personal identity. While this concept is relevant to the preceding

discussion of therapeutic implications, opportunity goes beyond application of beneficial

treatment. Thinking more dialectically may benefit offspring dementia CGs, but the dialectics

and ambiguity they encounter may serve as beneficial challenges and lead to personal growth.

That the CGs in the current study were willing to share about their experience, expressed

appreciation and benefit for the books related to caregiving provided to them, and related valuing

and making efforts to learn from their experiences suggests openness to growth opportunities.

While each CG should define and guide their own growth, this potential openness is instructive

to those who lead support groups, design physical and online programs, and serve CGs. Two

examples are webinars offered by the FCA, *Harvesting the Spiritual Fruits of Caregiving as a*

Way to Cultivate Wellness (Sherman & Weiner, 2014) and *Grit, Grace, and Resilience: The*

Story of Successful Caregiving (Dulaney, 2017).

Implications for Social Change

This study found no evidence that the fragmented dementia caregiving system in the US

(Feinberg & Levine, 2015) is becoming any more systematized or that PCPs or the medical

community are attending to the needs of dementia CGs.

The need for systemization. The case was made in Chapter One that CGs are the

invaluable (Reinhard et al., 2015), indispensable (Schulz & Eden, 2016) backbone of elder care

(Redfoot et al., 2013). The cost of not meeting their needs is too high for society, CRs, families,

and the CGs themselves. Yet when CGs need a break or additional support and must search it

out themselves (P), believe the CR's condition prohibits finding help (S), cannot find services at

the appropriate level for the CR (J), or cannot afford services (J), CG needs are not met.

Research has shown that dementia CGs experience stress in the process of seeking services

(Stirling et al., 2010). The very fact that these CGs did not complain about the formal caregiving

system suggests they did not have awareness that there could be more services and greater

service availability, a finding previously observed (Egdell, 2012). Calls for increased

systematization of information needed for dementia CGs (Wald et al., 2003) and for systematic

infrastructure (Jansen et al., 2009) remain unanswered. However, BOLD, discussed in Chapter

Two, has since been signed into law. BOLD holds promise for greater systematization, but it

must be prioritized. Also, the mandate that funding be used for, along with other important

emphases, "the needs of caregivers" (BOLD, 2017) must not be an afterthought.

   The medical community. These CGs did not appear to have experienced integrated care

for their mothers or to find their PCPs to be a one-stop shop for information and resources

(Sutcliffe et al., 2015). They found medical appointments for their mothers to be time-

consuming and burdensome. That PCPs are in great demand in the US and have heavy

workloads is common knowledge. This section is not a critique of their hard work, but a concern

that, as currently structured, the medical community is not meeting the needs of dementia CGs

whose support is vital to the CRs. Systematization of the broader caregiving system must

consider expansion of integrated care and purposeful inclusion of PCPs in the system. To reduce

the burden of medical appointments, home visits by a medical provider could greatly help the

caregiving dyad, as this researcher had the privilege of experiencing when her aunt lived with

her. A more realistic option would be to purposefully expand telemedicine for PWDs and their

CGs. Two CGs (J, E), rather than their mothers' physicians, were the initiators of their mothers'

dementia medical management (J) or diagnosis (E). One CR, despite the CG (D) reporting many

medical appointments, had not been given a formal diagnosis. The researcher herself had to

initiate basic cognitive screening with her father's PCP. This reinforces the call to address the

need for PCPs and other providers to have greater awareness and knowledge of dementia, the

lack of which negatively impacted quality of life for CRs and CGs (Sutcliffe et al., 2015).

Caregivers and care recipients. PWDs and their CGs have every right to expect and even to demand services they need yet continue not to be "respectfully involved as an ongoing knowledge source" (Galvin et al., 2005, p. 2). While both have been included to a limited degree in development of dementia related programs on the national level (RAISE, 2018), it is essential that the voices of those most knowledgeable of the needs, dementia CGs and PWDs as they are able, are involved in the development of the centers of excellence mandated by BOLD (BOLD, 2017). Doing so was a key aspect of development of exemplary government policy in Wales (Cascioli et al., 2008). It is hoped that the current work can both instruct CGs and provide one avenue for their voices to be heard.

Dissemination. Knowledge cannot bring about social change if it is not disseminated. For that reason, one or more articles based on the findings of this research will be submitted to relevant journals. The FCA, whose listing supported finding participants for this study, will also be provided significant findings.

Further Areas for Research

The findings that hinted at reverse attachment in dementia parent care, the observation that object relations theory is understudied in this population (Loboprabhu et al., 2007), and the significance of care for one's own original "'maternal object'" (Loboprabhu et al., 2007, p. 148) suggest attachment in parent care may be a rich area for further inquiry. Previous work on ambiguous loss in caregiving and the role of a "psychological family" (Boss, 2011, p. 79) as a caregiving team, have been supported by these findings, suggesting further research in those areas. Being from a blended FoO impacted and complicated caregiving for three CGs, evidence that studying the relationship between FoO status and the experience of offspring CGs may be beneficial. Furthermore, the influence of FoO for these CGs validates the importance of

continued work to better understand offspring caregiving within the family system. Given the fit

to these CGs, a Bowenian family systems framework for such caregiving research might be

beneficial. This study focused on a narrow group of CGs in order to better understand the mental

health needs of those at higher risk of emotional strain. However, further work looking at the

specific needs of understudied CGs is also needed. Examples include Native American CGs,

male offspring CGs, and CGs of persons with early onset dementia or specific subsets of

dementia.

The findings regarding dialectics, interpersonal stress, and emotional distress suggest that

the application of DBT skills training to CGs (Drossel et al., 2011) may be of value. A nine-

week DBT skill training for CGs increased problem-focused coping in participants (Drossel et

al., 2011) and problem-focused coping is associated with less CGB (Papastavrou et al., 2007). It

should be noted the work by Drossel et al. (2011) was not an RCT and its participants were a

subset of dementia CGs who had an elevated risk of elder abuse. Thus, its application to other

dementia CGs is unclear. However, CG needs identified in the current study for respite and

thriving parallel the DBT skill training outcomes of decreased fatigue, enhanced emotional well-

being, and measurable improvements in depressed mood (Drossel et al., 2011). The lack of

systematized services for CGs in the current study might be helped by DBT skill training

addressing help-seeking behaviors (Drossel et al., 2011). Also, DBT in general focuses on

interpersonal effectiveness, (Linehan, 2015) which has potential to decrease the impact of FoO

conflict on CGs; and on mindfulness, emotion regulation and distress tolerance (Linehan, 2015).

Thus, it would be worthwhile to further investigate DBT skills training for dementia CGs. Such

an investigation is further supported by the relevance of dialectics and potential benefits of

increased cognitive flexibility identified by the CGs in the current study. Despite the potential

for real benefit from DBT skills training for dementia CGs, in a review of articles that have cited

the work of Drossel et al. (2011), there is no evidence that further research on applicability of

this treatment to dementia CGs has been done.

Final Summary

The current study sought to deepen understanding of CGs of a parent with dementia.

Chapter One provided explication of the need and purpose of this study and the specific research

questions it asks. The conceptual framework, the research method with its rationale, and

definition of key terms were also given. Lastly, the chapter discussed the limitations and

significance of the study.

Chapter Two, an extensive review of the caregiving literature, provided further rationale

for the study and its chosen methodology. Areas explored were the family, caregiving, and

societal systems; the dyadic CG-CR relationship; CG identity; making sense and finding

meaning; and the mental health needs of offspring dementia caregivers. Qualitative work was

given specific attention for each topic. The chapter concluded by discussing contributions of

IPA to the topic of dementia caregiving. The literature review revealed that offspring dementia

caregiving is a complex phenomenon, not well understood, with little clarity regarding how best

to meet the mental health needs of those CGs.

The research methodology of the current study is the topic of Chapter Three, which gives

the rationale for the choice of IPA and procedural details. Means of assuring validity of the

study are explicated, along with the research question, the context of the study, and ethical

considerations. Ethical consideration further led to a discussion of the role and person of the

researcher, with awareness of the hermeneutic factor in IPA.

Findings, the topic of Chapter Four, are given for each individual participant, answering the research question of how they describe their caregiving experiences. The remaining research questions are then discussed. Their interface with the societal and formal caregiving systems were often absent or not supportive. Family systems, often conflictual, influenced these CGs significantly, exacerbating or revealing preexistent dynamics. The roles of trust in family relationships and team in caregiving were highlighted. Challenges to CG identity, including loss of mother as mother, were discussed. These CGs all engaged in meaning-making, their values were both challenged and shaped by caregiving, and their experiences were dialectical. Each CG's experience was idiosyncratic, but there were many similarities, discussed in Chapter Four. The mental health needs experienced by these CGs were neither urgent nor intense, but they described a lack of thriving, and potential needs for cognitive flexibility, hope, relief from family conflict, respite, and autonomy, while also identifying positives and growth opportunities.

The current chapter presents evidence of quality in the study and explores limitations. It concludes this work with a discussion of the relevance of the findings for mental health providers, policy makers, the medical community, CGs, CRs, and researchers.

Final Thoughts

To state that these CGs are doing difficult and important work is hardly a new observation but is reinforced by these findings. The participant CGs whose stories are told here are devoted copers, philosophers, humorists, learners, and wing-clipped birds yearning to fly. It is hoped that this current work can deepen understanding of the caregiving experience so that mental health counselors and others who provide services and support to dementia CGs can better ease some of their burden, support their personal growth, and even normalize their clipped wings. There may be limitations on the capacity of dementia CGs to fully thrive in the midst of

caregiving, but they can move in that direction and, in learning from the experience, potentially

develop stronger wings for greater thriving in the future. Noting that to care is to be human

(Heschel, 1997), dementia CGs are profoundly human, sometimes doing heroic work.

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Appendix A: Search Terms as Entered into EBSCO Quick Search™

Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND offspring or child* or son or daughter AND "family system"

Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND offspring or child* or son or daughter AND "caregiving system"

Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND offspring or child* or son or daughter AND "societal system"

Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND dyadic relationship

Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND identity

Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND meaning or "meaning-making" or existential

Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND offspring or child* or son or daughter

Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND offspring or child* or son or daughter AND counseling or psychotherapy

Daughter or female or wife AND Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND counseling or psychotherapy

Caregiver* or carer* AND "mental health" or stress or burden AND Dementia or Alzheimer* or NCD or "neurocognitive disorder" AND Interpretative Phenomenological Analysis or IPA

Appendix B: Semi-Structured Interview Guide

Thank you so much for being willing to participate in this study. [Discuss the consent form and answer any related question.] The purpose of this research is simply to better understand your caregiving experience. I want you to feel free to express yourself. My role is primarily to listen. Do you have questions about this interview?

The experience of caregiving
What has it been like for you, caring for your mother?
(prompts as needed)
        How has this changed your life?
        What is your day-to-day life like caring for your mother?

How has this affected you?
(prompts as needed)
        Emotionally?
        Spiritually

Do you have needs for yourself that are not being met?
(prompts as needed)
        What do you think prevents these needs from being met?

The family system
Tell me about your family of origin.
(prompts as needed)
        Before caregiving
        Since caregiving
Tell me about your relationship with your mother.
(prompts as needed)
        Childhood
        Before he/she had dementia
        Now

Tell me about your experience of caregiving in regard to your sibling(s).
        Cooperation
        Conflict

Meaning and making sense
What gives your day-to-day life meaning now that you are living with and caring for your mother?

Appendix C: Caregivers' Journals

CGs were given the interview guide prior to the interview and asked to journal. Two CGs returned their journals. Below are their responses, with any identifying information removed. The purpose of journaling was to provide data for triangulation with finding. Thus, the responses below are notated for when they support findings, conflict with findings, or provide information that was not in the interview data.

Underline: Confirmation of findings
Bold: Conflict with findings
Italics: New information

The Experience of Caregiving

1. **What has it been like for you, caring for your mother?**

   Debbie: It has been an up-and-down experience. The longer it drags on, the *less willing* and more *resentful* I become. It started off as hiring 24/7 care for two years; then 2 years where my husband and I moved in with her, and now it has been two years of caring for her in our home.

   Ann: Like caring for a child.

2. **How has caring for her changed your life?**

   Debbie: I tell folks my wings have been clipped. We never had children, and my husband and I have had the freedom to pursue our vocational paths and go and do as we please. Now, it has become trying to work around care giver schedules, work schedules, and adjusting to vocational changes.

   Ann: - Have to plan ahead to do things
   Everything takes longer.
   Meals

3. **What is your day-to-day life like caring for your mother?**

   Debbie: Fixing meals that she likes and can eat versus just eating on our time schedule or on the go OR *prepping the day for any caregivers to care for her that day. Making sure I am available to come back at the time the caregivers need to leave and/or being available to answer questions or problems as they come for caregivers.* Navigate my schedule, husband's schedule and caregiver's schedule. Constantly repeating myself and answering the same questions over and over and over again. Writing out notes for her to read that she may or may not remember to read. Posting signs to direct her. *Figuring out how best to keep her occupied on things she enjoys.*

   Ann: Can't leave her alone
   Showering
   Cleaning
   TV Watching

4. **How has caregiving affected you?**

   Debbie: *I hate the caregiving role, and I am pissed* that my parents did not listen talk this

<u>out more with their children.</u>

a. **Emotionally?**

Debbie: I have *always had moments of depression and anxiety when life gets overwhelming* and then is no different. The *difference is that it is more prominent (pops up more and last longer).* I was aware of all the care giver strategies, but as different life events happen, I find I have to <u>continually re-evaluate my strategies.</u>

Ann: Doesn't know I'm daughter
-sister
- sometimes Mom
<u>Sad</u>
Sometimes angry
<u>Not how we saw retirement</u>

b. **Spiritually?**

Debbie: I do rely on my faith to help, but there are *many times I am pretty pissed at God*. As a pastor, counselor and teacher, I am very <u>aware of all dynamics and self-care</u>. Right now, I tell people I find myself <u>bitching a God more </u>these days; however, I also <u>recognize God can take it.</u> I feel like the Psalmists. I just find that many people of faith are unable to handle and respond well to my <u>honest dialogue with God.</u>

 Ann: *Sometimes angry*
Don't understand
<u>Lost prayer warrior</u>

5. **Do you have needs for yourself that are not being met?**
    Ann: <u>Privacy in home</u>
       <u>My children don't always understand</u>
       <u>Hard to plan</u>

The Family System

6. **Tell me about your family of origin.**

a. **Before caregiving.**

Debbie: Father, mother brother [2 years older] , myself, younger sister [8 years younger]
I had a good relationship with both brother and sister <u>and mother</u>;
<u>an OK relationship with father.</u>
<u>I would say that my husband and I have been the most emotionally stable throughout our adult life.</u>
<u>Brother with substance abuse</u>
<u>Sister has struggled </u>with *[mental health issues]*
<u>My father was in good health and was my mother's caretaker (multiple health issues) until multiple strokes lead to his death six years ago. That task then fell to the three children,</u> which *placed stress on what relationships were there*. Then my <u>brother's drinking escalated, which added stress to the situation, </u><u>leading us to move in to take care of Mother.</u>

Ann: <u>Mom, Dad - 3 sisters</u>
    <u>Oldest</u>

b. **Since caregiving.**

Debbie: <u>Mother</u> loves all her children, but she *could never acknowledge or accept our weaknesses of failings*. So that carried itself into the siblings trying to work together for her care. . . . As his <u>drinking escalated</u> after father's death, he became more <u>verbally abusive to . . . [sister]</u> her. My sister asked me to take over because <u>she could not handle it</u>. That is when my husband and I decided to <u>leave our jobs to move in with her for a year. . . .</u> My <u>brother then turned his anger on me and my husband</u>. After two years, my husband and I <u>took two jobs back at our home and gave Mother the option to go back to 24/7 care or move in with us. She chose the latter</u>. . . . <u>[brother ill]</u> My sister did not want to deal with that, so I and my husband left to go to . . . to meet with the doctor's. . . . as we were making plans to transfer him into a hospice, <u>he died. My husband and I were left to take care of his estate</u>. While <u>my sister and I still have a fairly decent working relationship</u>, I find myself *less inclined to "care" about her life*. I told my husband once that I am not sure I want a relationship with her after this is all over. <u>I am finding "family" to be unhelpful and a drain on my life.</u>

7. **Tell me about your relationship with your mother.**

a. **In childhood.**

Debbie: I think I had a <u>good relationship with my mother</u>. She was the one that was most patient, loving, and available. Usually, she would be the one that would listen and tended to be more <u>gracious</u> in her responses to her children. <u>We had our spats</u>, and we definitely saw the world in different ways, but we always remained in relationship. <u>She told me later I was always the independent one.</u>

Ann: <u>She took care of her mom</u> - <u>Mom always a worrier</u>

b. **Before she had dementia.**

Debbie: Our relationship was always good. I stayed in touch with all members of my family. <u>Dad and I had a better relationship later in life</u> for the most part, so we all got along well during family visits. However, I think my other two siblings were more attached to my Mother; we all had problems along the way with our father. About two years before he died, Dad tried to get Mother to consider moving to a local CRC, but she resisted. They both would privately say they thought the other was showing signs of memory problems. I did a screening on them both, and it showed they were both showing some signs. I encouraged them to both bring it up to their PCP. That went over like a ton of bricks. All the kids said we would help them go through things and help them move, but *she was adamant about not moving*…one of her less admirable qualities. When she was adamant, she was adamant.

c. **Now.**

Debbie: The essence of her <u>personality is still the same. She is still that gentle, inquisitive, caring person, and adamant person.</u> She is actually an easy person to

care for, or we would not be doing this. All of the caregivers describe her as sweet, funny, and curious. They ponder at how she can remember some things and not others. I, too, marvel at how her brain works (or not). Up to this point, she <u>has not exhibited any anger or agitation</u> I see in other people with dementia. She is unable to function on her own and has to be given lots of reminders and directions. She remembers her children, and her brothers and sisters, but she is unable to remember nieces and nephews. She can remember things from long ago, but can't remember what I just told her. Some days she remembers her caregivers and some days not. I do wish she would have been and would be open to going to a caregiver facility; I think that would be the most helpful for my sister and I. However, she is adamant about NOT going there. I <u>still like my Mother</u> and *want to help care for her*; I <u>just did not bargain for ALL of what I got with my family</u>.

8. **Tell me about your experience of caregiving in regard to your sibling(s).**

   a. **Cooperation**

   Debbie: <u>In the beginning, we three tried to work together to care for her</u>. We hired 24/7 care while we would each try and take some shifts. My brother would come up for one week a month, and I would come down for 5 days a month. My sister would fill in, and we had one consistent caregiver, who could stay around the clock. Unfortunately, my brother's substance use hijacked his brain. <u>If he had been clean and sober and in counseling, I think we could have managed and cooperated for a longer period of time.</u>

   Ann: right now working pretty well - one sister still works fulltime.

   b. **Conflict**

   Debbie: <u>Taking care of Mother has placed stress on my relationship with my siblings.</u> We <u>could have probably survived our spats and worked through it IF my brother had been in a better place.</u> My <u>sister and I can usually work through our conflicts</u>, but it is dependent on how stressed we are each feeling. I do think *it has changed our long-term relationship*, and I am not sure what that will look like we our mother is no longer here with us.

   Ann: just getting away and making those plans

Meaning and Making Sense

9. **What gives your day-to-day life meaning now that you are living with and caring for your mother?**

   Debbie: I focus more on *finding joy in my life* and that <u>this will not last forever.</u> I think <u>it will help make me a better pastor and counselor</u>. I was always understanding and empathetic, but this adds a new dimension. I would say that I have *good resources to fall back on:* my faith, education, good friends, support of husband, and financial resources to help. Many people I have worked with in the past lack some of those helpful support systems. <u>I am also learning how it is really a day to day adjustment.</u> What do I need, what does she need, what does my marriage need, what <u>life changes cause me/us to have to rethink strategies?</u>

   Ann: <u>Knowing this is what I am here for right now. Moved here 4 years ago.</u>

Appendix D: Tables and Figures

Table 1

Demonstrations of Validity: Based on the Criteria of Yardley (2000)

	Sensitivity to Context	Commitment & Rigor	Transparency & Coherence	Impact & Importance
The interview guide	Are the voices of participants prioritized?	Does the guide fit the research questions and the literature review?		
Choice of participants	Does the sample fit with the intent of the study?	Does the sample fit the research questions? For IPA: Is the sample homogenous?		
Demographic survey	Is relevant sociocultural context data obtained?			
Participant journals		Are the journals used for triangulation while still giving priority to the interview data?		
Quantitative measures		Are measures used for triangulation while still giving priority to the interview data?		
Relevancies in literature	Is there evidence the researcher was sensitive to relevant sociocultural contexts?			
The literature & theory	Are the following connected to the literature and theory: The interview questions Corroborating measures The analysis	Is there evidence the researcher deeply engaged with the topic?		
Data collection and analysis		Is there evidence the researcher deeply engaged with the topic?		
Provision of raw data	Are sufficient participant quotes provided to demonstrate grounding in the interview data?	When triangulation occurs, are raw data provided?	Are the connections between the raw data and the interpretations clearly demonstrated?	Is there sufficient raw data to give import to the voices of the participants?
Person of the researcher		Is there evidence of professional and personal engagement with the topic? Does the researcher have the skills to conduct an IPA study?	Are her biases & expectations transparent?	

	Sensitivity to Context	Commitment & Rigor	Transparency & Coherence	Impact & Importance
Artifacts		Does the researcher report keeping artifacts to provide to supervising faculty?	Is the research process transparent?	
Member checking		Did the researcher seek feedback from participants? If there were discrepancies, did the researcher privilege the participants' voices and show evidence of wrestling with the implications?		
Audit trail journal		Does the researcher report keeping an audit trail journal and making it available to supervising faculty?		
Faculty interactions		Is there evidence the researcher sought feedback related to the rigor of the study? Is there evidence the researcher provided an audit trail summary to faculty advisors?		
Self-reflection statement			Are the researcher's role, activity, and experience of this study transparent?	
The final product	Have Participant voices been privileged throughout?	Is it complete?	Is there a coherent framework? Is there coherence with IPA? Phenomenological: Is there understanding the experience of these CGs? Interpretative: Is there readily identified hermeneutic activity?	Does the reader find it to have impact and be important? Is there an addition to the knowledge base regarding: These CGs Their mental health needs The role of the family system in the caregiving experience Is there a new perspective? Might that contribute to mental health treatment
The final product	Have any claims been made that the data do not support?			
The final product	Is there evidence that the researcher followed the planned procedures or appropriate explanations for not doing so?			

Table 2

General Table of Themes

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Societal system: *Little interface*	+ the divine	+ neighbors + friends + houses of worship + the divine ~ wants employment ~ ending co-residence	- small, shrunken world - "dementia friendly" [1] + friends + extended family + houses of worship + the divine	- "dementia friendly" [1] + friends + the divine	+ friends	+ extended family + houses of worship + the divine ~ employment ended co-residence
Caregiving system: *No systematized services* *No integrated PCP care*	+ day programs + support group	+ in-home care - medical care time consuming	+ day programs + in-home care	++ day programs ~ seeking in-home care +transportation service - medical care time consuming	~ day programs - medical care time consuming - initiator of Alzheimer's disease and related dementias management- wait for being paid for care	~ senior apartment - medical care time consuming - initiator of Alzheimer's disease and related dementias dx - a little decision-making help
Family System *Dyadic relationship* *None in a currently conflicted relationship.*	+ pleasant + not demanding + pretty compliant + grateful - behaviors - does not know as daughter + hx of good relationship ~ ltd availability in childhood	+ very sweet, patient + easy to get along with - pretty self-centered - stubborn - less social - less emotionally available	- behaviors - does not know as daughter - not able to connect + history of good relationship	+ good + generous - trouble - more negative - hx of conflicted relationship ~ ltd availability in childhood + had healed the relationship + loving caregiving relationship despite deep past hurts	++ relationally "better" + no longer faultfinding - less interactive - hx of conflicted relationship ~ ltd availability in childhood - recent hx of estrangement + loving caregiving relationship despite deep past hurts	+ grateful - less an emotional support + history of good relationship

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
FoO *FoO is relevant to caring for a parent (all)* *FoO conflict (all but A) or harmony (A) appears to mutually influence the caregiving experience.* *Some issues & relationships may remain unresolved*	++ Uniquely harmonious ++ caregiving team with sisters	- family hx of alcoholism - conflicted relationships -- sibling issues the difficult part - sibling help only early on	- Current passive abdication to CG ~ brothers supportive verbally	- family hx of abuse - conflicted relationships ~ blended family -hated & resented by siblings - no help from siblings + emotional & spiritual work are beneficial in dealing with family conflict in caregiving	- family hx of alcoholism - conflicted relationships ~/- blended family - cutoff from stepsiblings - little help from brother + emotional work is beneficial in dealing with family conflict in caregiving	- family hx of trauma - conflicted relationships ~/- blended family - Current passive abdication to CG + help from brother - little help from sisters + emotional & spiritual work are beneficial in dealing with family conflict in caregiving
Exacerbator or revealer *FoO conflict (all but A) or harmony (A) appears to mutually influence the caregiving experience.*		- with caregiving family issues emerged	~ caregiving may exaggerate what is already happening - denial -noncommunication		+/- learned through caregiving that stepsiblings not close	+/- through better understood sibling dynamics
Opportunities *To create a psychological family based on a foundation of who they can trust* *For personal, relational, or professional growth* *Pain of family conflict is real.* *Opportunity a subtext in J's story, to deal with:* *false messages of childhood* *having needs* *relational growth* *open to healing* *with mother* *with stepfather* *accepting cutoff* *with step siblings*	++ Trust amongst her sisters/ caregiving team + + learned who is in their "psychological family"[2] -+ includes isters	+ learned who is in their "psychological family"[2] - does not include siblings - cannot rely on sibling(s) + able to anticipate benefits in the future for her work in mental health	+ learned who is in their "psychological family"[2] ~ includes siblings minimally	+ learned who is in their "psychological family"[2] - does not include siblings - cannot rely on siblings + release FoO conflicts to focus on her love for mother	+ learned who is in their "psychological family"[2] - does not include stepsiblings ~ includes brother minimally + my relationship with my mom is the best it's ever been"	+ learned who to trust & rely on + learned who is in their "psychological family"[2] + includes brother - includes sisters minimally or not at all + boundary setting + implementing things learned + increased acceptance

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Roles & the decision to care *shaped by FoO expectations & dynamics* *Gender may play a role.* *Gender & position in the FoO had mixed influence* *complicated by blended family dynamics* *the traditional[3] FoOs the CGs were the oldest or only female*	~ parent expected her to be CG Traditional family: ~ oldest & oldest daughter	~ the responsible one ~ the stable one ~ parent expected her to be CG Traditional family: ~ middle child, oldest daughter	Traditional family ~ youngest child, only daughter	- parentified as a child CG ~ the responsible one ~ complicated by blended family dynamics	- parentified as a child CG - complicated by blended family dynamics	- sibling not expected to be CG ~ cultural expectation for youngest daughter to care ~ complicated by blended family dynamics
Caregiver Identity *"lack of reciprocal validation"[4] in dementia care can cause CGs to lose "remnants of their own identity "[5] ** *CG depression was highly associated with loss of self [6]* *caregiving can restrict one's life, which "may be mirrored in the loss or shrinkage of self"[9] **		+ trying to preserve her "own life story"[7] + aware of risk of engulfment in CG role [8] Feeling more depressed *	identified as a mother & wife & as daughter/caregiver, which overwhelms * - small, small world has shrunk quite a bit *	+ past work on identity	+ past work on identity ~ identified as an introvert + recognized related need for alone time - caregiving prevented meeting that identity-based need *	+ past work on identity

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena

Loss of mother as mother
    Role reversal
"her child/mother" [10]
 	
    altered identity related to mother
    not known by her
	- I know I've lost my mother	- not really the mother I once knew
		- I'm the parent, she's the child
			- I miss her
			- I've switched over from being . . . the child to the parent
			~distance myself from her emotionally
			~not thinking of her as my mom
			- doesn't really even look at me as her daughter anymore
				+ Not yet to that degree of functional loss
				
				~ Long-standing mother-daughter role reversal
					- I see her slipping away
					
					+ Improved relationship due to dementia personality changes
						+ Not yet to that degree of functional loss
						- Wished for emotional support from mother
						
						- bit of role reversal

Reverse attachment *dementia CGs may function as a "'maternal object' . . . [who provides] 'holding environment' of warmth & safety"* [11]	.		~ clearly attached to me . . . her primary CG ~ attached to me . . . more so than anybody else -very fixated on having me around ~ the one her mother come to for security - in moments without CG, untethered.		- at that stage where she wants to be with me all the time - can't be left alone at all - like we're attached at the hip	

Loss of freedom
    None suggested they had lost their noncaregiving social identities
    Constancy of caregiving led to losses in previous self-directed lifestyles & spontaneity
		- was happy with the route that I was going six years ago			- I feel like I don't have my own life *	

* These statements suggest that there is a potential for a diminished self or sense of self.

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Making Sense *what gives their lives meaning in caregiving* *finding meaning is idiosyncratic*	+ I am where I'm supposed to be	~ I wish I could say every day I can find meaning, but that's not true	+ this has got to be the best place. This has got to be good for my mom	+ Oh, well, I love her, you know? I love her, & . . . it pleases me to know that she's taken care of & that she's well & that she's healthy	+ Giving her the best quality of life that she can have	+ this experience . . . as a caregiver helped to . . . value the importance of treating elders with dignity, courtesy, & respect
Adding Meaning *Via learning*	+ learning from difficult experiences that are here to teach us + helpful to learn more about the disease	+ found things that . . . added meaning to our lives + Education, staying in career			+ J was seeking to self-educated related to her mother's care - at a point she felt overwhelmed with information	+ learned a lot about patience & acceptance from caregiving & mother's e.g. + reading & self-reflection, led to enlightenment +learned to alter her expectations of others from author & a priest +learned to put caregiving into eternal perspective from a homily.
Gratitude & positivity *all referenced the positive & good in their lives* *saw the value of thinking positively* *appreciative*	+ realized need to start reading more positive things + caregiving team, husband, cousin + where living	~ kick myself in the butt . . . '[to do] that whole thankfulness & gratitude + husband, spiritual supporters, friends + inform future career	- really hard to . . . stay positive + there's some good stuff too, - - but . . . you don't really see the good stuff while you're in the midst of it. -You see the challenges, & . . . not really . . . the benefits + spiritual supporters, God + mother's enjoyment	+ husband, friends + mother's enjoyment	+ Glad to do it + friends + reconciliation with parents + where living + skills learned in traumatic childhood	+ caregiving team + opportunity to reflect + experience clarity & relief from AD dx + for the life lived - 0 trauma

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Accepting, adjusting & adapting	- day-to-day adjusting -adjustment to CR declines	- adjusting to parents aging - accepting lack of assistance ~ I don't have any gr& expectations at this point	- adjusting to CR behaviors ~ hang on to realistic expectations + trust God with what remains after doing one's best	- constant adjusting - adjusting to CR changing needs - accepting lack of assistance ~ it is what it is ~ doing the best one can	- accepting lack of assistance	- accepting lack of assistance - accepting negative reactions from family ` accepting one's own past decisions ~ realistic expectations ~ realizing what you can't control
Doing the best we can *recognizing their own limitations* *Pride & a positive sense of self resulted from doing their best*	+ inferred mother's satisfaction, + would never want to live alone + she does want to be here	+ I'm doing a good job	+ we're doing the best we can + I can treat her probably the best + there's not a perfect answer in dementia caregiving + fairly proud of dealing with what comes up	+ She is much healthier living with us than by herself + husband confirmed the good job + That part of me feels right + I feel like a good daughter	+ mother: I need you. Will you, will you come home?	+ I'm doing the best I can + mother grateful
Philosophical, faith, & spirituality *Values confirmed & challenged* *existing caregiving related values* *Caregiving's impact on values*	~ we do ıeed to take care of ›ur parents		~ keep our word [not] to . . . put her in a home - challenge to belief that life has value			+ older adults are supposed to be treated with dignity, courtesy, & respect reinforced value of treating elders with dignity , courtesy, & respect

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
The role of time		~ Time, a framework for caregiving - 6 years of caregiving - short term would have been better	- on a day-to-day basis it gets old, it gets tiring + appreciate today + make the most of what you can			
Present focus		+ future: no regrets, will be able to seed it as sacred, will inform future work	~ we don't know what tomorrow brings ~ all we've got anyway is one day at a time		+ be as present for her as possible	
Spirituality & faith *All referenced faith, spirituality, God or being blessed* *Ask* *Receive*	~ attending a Christian faith community (large and not connected + prayer	+ attending a Christian faith community + connecting to God	++ attending a Christian faith community + prayer + sustenance to make it through the day +blessings through others in her faith community.	+ meditating and doing deep body work and breath work and isolation tanks and meditation retreats and . . . spiritual growth + spiritual bonding with mother + asking of God + God's gift to me of wings of an owl, my totem animal + . love . . . and peace and . . . little more serene	+ mindfulness to deal with stress + given a gift + blessed by opportunity to reconcile	+ attending a Christian faith community + homilies gave her tools to deal with family and caregiving stress
Realistic faith spirituality & faith provided some support in care-giving, help to make sense of it, and are sometimes informed by it, but w/o being roseate	~ need to engage more with her faith.	+ down-to-earth relationship with God ~ no apology: bitching at God, not feeling caregiving was sacred, not a saint"	~ spiritual . . . ups and downs			- past hard to accept where she was in life + content w/doing her best + acceptance of others' reactions ~reframed caregiving as cross to bear, testing ground, purgatory of life journey & response is a basis of future judgment and eternal fate.

Dialectics
Dialectics contributed to meaning-making, but the topic is treated separately due to the extensive nature of this section.
In DBT, nondichotomous thinking & "comfort with ambiguity and change which are viewed as inevitable aspects of life" [12] are important.
Dialectics observed in these CGs' stories and has been found in other dementia CGs [13].
Dementia caregiving: ambiguities, changes, ambiguous loss [14]
Dialectics challenge CGs to making sense of caregiving and gives them an opportunity to develop dichotomous thinking

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Significant terms *"Every minute is torture; every second is precious"*[15]			~ dual truths ~ this is hard, but this is good ~ life is precious & this is not the way my mom wanted to live	~ both at the same time	~ bittersweet	
Positive-negative *statements that embodied the positive and negative simultaneously* *Thoughts and emotions in swing.*	~ things could be worse ~ described paradoxes in her mother (reads, does not understand; wants to help & cannot) ~ mother is in the care of her adult daughters yet does not remember her own adulthood ~difficult positive could be worse hard loss disappointment of coping effortful acceptance adjustment fatigue OK deep breathing	~ caregiving doesn't feel sacred and I'm sure it is ~ grousing, bitching, and whining at God and seeking for thankfulness and gratitude	~ there's some good stuff too but . . . while you're in the midst of it you see the challenges, and . . . you're not really seeing the benefits	~ it's all wonderful, and yes, it's all a burden	~ caregiving was stressful and bittersweet ~devastating upset oh, well really terrible awful reconciliation sweet	~ caregiving was a positive experience and a challenge . . . earlier on

Challenges were related to:
    ● mothers
    ● caregiving						

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena

Mothers.
   can and can't are apparent polarities that are simultaneously true of CRs:
   Things they cannot do - restrictions of dementia Things they can still do - hope and possibility
   dialectic truth: CR has some abilities and is going to lose them.
   once a competent adult now dependent on the CG, for whom the CR was their competent care provider CGs can in terms of abilities, cannot due to caregiving limitations. Ambiguous loss, "here but not here" [16]
   Dementia can alter personalities [17]
	~ I know that's gonna get worse
	
	- was herself a CG and lived in service of others from her own childhood
	
	- Now she's about a two or three year old whom I wouldn't trust . . . at the stove
	
	- I can't even just sit in bed and read a book or just run out to the grocery store
			- not able to connect
			~ distance self from her
			~ not think of her as mother
				+ was a really positive person
				- more negative
				- in past hate and angst and frustration and hurt
				+ had healed
				+ under it all is the love
				- with a lot on top of it
				- resentment, anger, self-pitying: vascular dementia personality changes? [18]
				~ good and trouble
					- long conflicted relationship
					+ the best it's ever been
					~ Alzheimer's related personality changes
					- guilt
					~ but that's the truth though	

Caregiving
   limitations in effectiveness of caregiving reflected dialectics
dialectics in the guilt
	- lack of positive spontaneity
	- must be prepared for spontaneously needing to react to whatever . . . she might be into/ on guard
	- must plan ahead for basic tasks
	   - unable to truly plan, we don't know what tomorrow is gonna bring
		+ caregiving was fine
		- moments where it is not fine
		- solo caregiving was not fine
			+ can keep her safe, fed, clean - cannot meet all of her needs
			
			+ can talk self down from guilt usually
			- does not make it go away
					- cannot do everything, overwhelming
					
					- guilt ridden, feel like not doing enough for her
					+ want to give her best QoL
					- risk of being at her expense	

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Opportunity *Dialectics provided opportunity for personality growth*		- that's not true re: finding daily meaning in caregiving + I can look back someday and say, 'I'm glad I was able to'"	~ struggle and challenge to belief that life has value + opportunity to develop cognitive flexibility to hold both beliefs ~ there's not a perfect answer for this kind of a disease	+ self-defining contrast vs. siblings, do the right thing + That's who I [am]. I have to do the right thing		+ opportunities to better understand and be aware FoO dynamics + learn who she could trust and rely on ~ identified unspoken dialectics her trauma free childhood in a household where everyone else had trauma hx ~ response to whether caregiving had made her more aware of sibling dynamics "Yeah. No, yes. The answer is yes"
Mental health needs birds with clipped wings: "They're OK but they can't fly" [19]		- my wings have been clipped + fine ~ it's not a horrible, um, life - I really do not like solo caregiving ~I don't have any grand expectations at this point				
Challenges These CGs' challenges reflect their needs for: ● coping w/ inevitable disease progression ● sense of autonomy		● opportunities to rejuvenate and rest ● harmony				● breaks from the repetition and constancy ● hope

Disease progression
 	
    continuous losses
 	
    workload
    inevitability
	- know that's gonna get worse		- things are gonna get worse.
			- You're gonna lose another ability . . . another memory
			- a lot more intense
			- there's nothing you can do about
				- a lot more time	- she's been able to do less and less
					- I see her slipping away	

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Depleted *Due to disease progression, caregiving demands, and limits on meeting her needs* *depleted* *Exacerbated by not enough sleep* *Other sources of depletion*	- not enough sleep		- dealing with the inevitably of the disease progression (above) causes her to feel some days just tired - cannot meet all her needs - you're so depleted and the needs are so overwhelming - I am beat. I am exhausted - weary, and discouraged, and missing her - not enough sleep ~ The rest of my job is . . . trying to take care of my family	- I get frustrated and I get exhausted and I wish everyone wasn't so needy - It's exhausting - draining - angry and overwhelmed and exhausted - when everyone's on me at the same time. Then I get very upset	- cannot do everything - not enough sleep	
Ground Hog Day *Verbiage reveals frustration with repetition* *Routine* *Personal reasons the reputation may be hard*	- a lot . . . a lot . . . over . . . over . . . again . . . again . . . again	- repeat, repeat, repeat, repeat, repeat - explain this . . . 10 times - she will have eaten whatever it is 20,000 times and ask, 'What is this?' - cannot deviate in-in any way from. routines, it throws her ~ she gets easily bored	- overwhelmed by day-to-day repetitive - There's a lot of repetitiveness in caregiving - there's nothing you can do about - the same conversation every day - It's hard to have a positive outlook all the time when . . . every day is gonna be the same	+ mother less advanced dementia. Did not report repetition.	- It feels like it's Groundhog Day. Yeah. A lot – a lot - we have a discussion about the food again -she'll . . . show me each one . . . like I've never seen it before - repeating, repeating, repeating - I've heard that 30 times today - is emotionally triggered by the repetition	+ mother less advanced dementia. Did not report repetition.

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena

Loss of Freedom related to mental health
 	
Loss of self-direction in day-to-day life re:
	- relaxation
	- household activities
	- personal care such, e.g showers and sleep
	- meals
	  - not . . . what my mom would do
		~before caregiving had really good rhythm
		- relaxation
		- meals
		  - our menu planning has been curtailed
		  she likes the same things all the time
			- relaxation
			- household activities
				- I feel like I don't have my own life
				
				- relaxation
				- household activities
					- re freedom: I need it. I need it. Yeah. I, uh, I really need it
					
					- relaxation
					- personal care such as sleep
						- did not verbalize & mother in early stage of AD

Constancy, a particular challenge to freedom
 	
Leave her alone?
	- she has to be with you at all times
	- even at night
	- When apart, she come[s] looking
	
	- did not mention, but likely cannot be left alone
		- did not mention, but likely cannot be left alone	- I've always got to be focused on my mom
			
			- did not mention, but likely cannot be left alone
				- had been able to leave her mother alone, but at the cost of:
				  - constant burden
				  - angst
				  - worry
				  - cannot fully relax when out
				- could no longer be left alone
				  - required changes part of constant adjusting
					- she wants to be with me all the time, every second
					- like we're attached at the hip
					- even at night or when trying to rest during the day
					- When apart, she wants to go out front looking for me- can't be left alone at all
						+ mother less advanced dementia, apparently able to be left alone.

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Family conflict *Lack of support from siblings* *Relevant verbiage related to FoO* *The role of trust - "psychological family"* [2]	++ Only CG reporting FoO and CG team harmony ++ strong sense of gratitude ++ a caregiving team with sisters ++ learned who is in their "psychological family" [2]	- FoO conflict -- sibling conflict incredibly hard to manage -- sibling conflict a source of stress and upheaval - help only early on - more depressed - pain in the neck - incredibly hard - the difficult part ++ learned who is in their "psychological family" [2]	- verbal support only ++ learned who is in their "psychological family" [2]	- FoO conflict - minimal help from 1/3 siblings - hate me and resent me - angst ++ learned who is in their "psychological family" [2]	- FoO conflict - minimal help from 1/3 siblings - pretty devastating - awful ++ learned who is in their "psychological family" [2]	- FoO conflict - little to no help from sisters - brother very helpful - a sucker punch - a slap in the face - a gut punch ~ learn who I can trust and who I can rely on, "psychological family" [2]
Hope *CGs referenced* *No- despair of hopelessness* *No - hope* *Yes - positives* *Yes - future* *Little positives and future together.* *Hopelessness could be altered by CG self-efficacy and beliefs in ultimate meaning* [21].	- like taking care of my children all over again, but with reverse development ~ planning for mother's declines	~ planning for mother's declines ~ approaching an end to coresident caregiving + I will look back without any regrets + caregiving will inform my work I have to do in the future	~ planning for mother's declines - not much to look forward to with dementia	~ planning for mother's declines	- like when my daughter was little but more challenging ~ planning for mother's declines - uncertainty and anxiety re: future	~ planning for mother's declines

Summary

OK but not thriving, like a bird with clipped wings.

    None of these CGs presented as having urgent or intense mental health needs.

    All could name positives in their lives and they were

    All were making efforts to cope with and process their experiences.

Primary mental health need arising from this research would be to be able to fly or thrive.

Dialectically, a mental health need to thrive and to some degree caregiving limits their capacity to thrive. (from Chapter One: "optimally . . . retain personal autonomy and yet, often sacrificially, meet the needs of the CR". [22]

Mental health needs identified that could move them closer to thriving:

    Cognitive flexibility, vis-à-vis dialectics   Enhancement of hope

    Harmony or at least relief from conflict in the family   Respite as they define it   Autonomy

Coping. Given the above mental health needs, how did these CGs cope or what do they suggest would help them cope?

   The means of coping are more idiosyncratic than the needs, suggesting that perhaps, even when individuals undergo similar circumstances, what is beneficial will greatly vary.

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Getting away a need *hard to get away* *beneficial*	- time away a challenge	~ time away that I need - time away a challenge	- time away a challenge	~ I run in the back and hide + brief time away and trips - time away a challenge ++ getting away really did my heart and soul tremendous good	- I need some respite - need for alone time - time away a challenge ~ try to figure out how to make that happen	~ no longer co-resident, mother in early stage of AD
Need to make a change		~ had already made changes to be able to continue caring. ~ as a solo CG, the pending change end co-resident caregiving			~ need to do something different to relieve the stress ~ necessary to continue caring ~ not at the expense of myself	
Without blame *none blamed their* *mothers for dementia* *related behaviors or the* *situation.*		+ it's not necessarily anybody's fault		- carried much of the family blame in childhood	+ increased stress not due to mother who was not really different ~ it was due to her own internal need for respite	- felt blamed for not communicating with siblings when she had put effort into doing so
Humor *Sources of humor* *Purposeful use of humor* *Shared* *Humor is necessary*	+ Purposeful use of humor to laugh it off + with caregiving team	+ exhibited humor in interview ~ ironies of dementia	+ exhibited humor in interview ~ caregiving itself ~ ironies of dementia + purposeful use of playfulness for mother's benefit	+ exhibited humor in interview ~ caregiving related events + Purposeful use of humor to make mother laugh + with mother + When you take care of your parents you have to develop a sense of humor + an alternative to tears	+ exhibited humor in interview + with mother + to counter frustration	

Theme	Ann	Debbie	Sarah	Penny	Jane	Elena
Reframing *not common amongst these CGs*		~ a counseling professional + reframes and rational narratives helped cope with family conflict	+ used a reframe to help her be less sad and more emotionally supportive of her mother ~ that reframe was to not think of her as my mom			
Trying and effort *Whatever means these CGs used to cope, there was evidence they did so effortfully*	- increasing positivity required working on it	- increasing positivity meant I have to really like kick myself in the butt - effort to deal with family - effort to deal with CR -self-care required effort	- to stay positive was really hard -effort to deal with CR - carried mother's emotional burdens	- effort to find what was best for their mother's care - using humor was effortful - obtaining additional services that would improve CG well-being, took effort.	-effort to deal with CR - effort to find what was best for their mother's care - obtaining additional services that would improve CG well-being, took effort.	- emotionally relied on by mother

Footnotes:

[1] (ASC, 2017, p. 39)

[2] (Boss, 2011, p. 79)

[3] For lack of a better term, here "traditional family" means a FoO without divorce with both parents in the home

[4] (Orona, 1990, p. 1255)

[5] (Orona, 1990, p. 1255)

[6] (Nichols, 2001)

[7] (Hodgetts et al., 2003, p. 382)

[8] (Skaff & Pearlin, 1992)

[9] (Skaff & Pearlin, 1992, p. 656)

[10] (Macaulay, 2014)

[11] (Loboprabhu, Molinari, & Lomax, 2007, p. 148)

[12] (Linehan, 2003)

[13] (Orona, 1990)

[14] (Boss, 1999, 2011)

[15] (Macaulay, 2014)

[16] (Boss, 2016, p. 270)

[17] (Khan, Kalaria, Corbett, & Ballard, 2016; .McKhann et al., 2011

[18] (Khan et al., 2016)

[19] (Anonymous, personal communication, January 2019)

[20] (Boss, 2011, p. 79)

[21] (Lopez et al., 2012)

[22] (Hodgetts et al., 2003)

Key:

+   positive (++ very positive)

-       negative (-- very negative)

~   neutral or ambivalent

DBT   Dialectical Behavior Therapy

Dx   diagnosis

FoO   family of origin

Hx   history

Ltd   limited

Mgmt. management

QoL   quality of life

Table 3

Tables of Specific Themes

Themes		Sample Participant Quotes	CG

Societal system:
   Little interface
	Caregiving system:
	   No systematized services
	     No integrated PCP care
		"My world has shrunk quite a bit."
		"Our life revolves around meals and . . . doctors' appointments."
		PCP "hasn't had her go to a neurologist . . . so I'm trying to see what our options are".
			Sarah
			Debbie
			Jane

Dyadic relationship *None in a currently conflicted relationship.*		"easy to get along with" "I told her everything . . .and she cried, and I cried. . . . After that we started healing our relationship." "My relationship with my mom is the best it's ever been."	Debbie Penny Jane

Loss of mother as mother
   Role reversal
   Altered identity related to mother
   Not known by her
		I'm the parent, she's the child."
		
		"She doesn't really even look at me as her daughter anymore."
		"Occasionally though, she doesn't know who I am."
			Debbie
			
			Sarah
			Sarah

Reverse attachment? *Daughter CG as the secure base*		"She is clearly attached to me . . . her primary CG." Sarah was "the one that's um, you know, to come for security." "It's kind of like we're attached at the hip."	Sarah Sarah Jane
Challenges to identity *Potential for a diminished self or sense of self*		"It's a very small, small world." "Since my husband has taken his job and, um, probably I get more depressed." "I feel like I don't have my own life."	 Debbie Penny

Evidence of the Positive in Caregiving

Positives & frequencies		Positive statements	Meaning-Making statements	Observation	CG
"Appreciate" "Helpful" "Thankful"	27	"Having my sister live here has helped tremendously." "I'm thankful for my home and where we live and who I'm surrounded by." "but on a positive side . . ." "very, very lucky"	"I am where I'm supposed to be" Experiences are "here to teach us" "I just recently realized that I need to start reading more positive things" "We're supposed to learn to be content." Prayer	Putting effort into the positive Formal religion a potential source of support.	Ann
Laughter	52	"God blessed me with a very good husband." "As a team, he and I work very well together." Mother is "very sweet, patient". "just doing that whole thankfulness and gratitude".	"Connecting to God." "Relationship with God is very down-to-earth." "In the long run I think it [caregiving] will be" sacred.	Putting effort into the positive Formal religion a source of support. Relational emphasis	Debbie
Laughter	92	Her mother was "pretty compliant usually". She "appreciate[d] . . . spiritual support um, from God to sustain me". "I'm actually fairly proud of" coping with caregiving. "really hard to . . . stay positive"	"Appreciate today" and "make the most of what you can". "All we've got anyway is one day at a time" God enabled her to "make it through the day." She received blessings through others in her faith community. Prayer	Positivity is not easy. Formal religion a source of support. Reported uplifts from spiritual community	Sarah
Laughter	18	"When you take care of your parents you have to develop a sense of humor". "I try and make her laugh. We try and have funnies every day". "You can either cry about it, or you can laugh about it."	"That part of me feels right." received "God's gift to me" of wings of an owl, "my totem animal." Meditation Asking of God	Valuing and intentional about humor/ humor to cope. Spirituality a source of meaning and healing.	Penny
Laughter	27	Caregiving was a chance "to reconcile with" her parents. "Blessed that we had this opportunity . . . [to]end on a positive note". "I'm . . . glad to do it"	"Be as present for her" as possible. Being able to reconcile, she was "given a gift" and was "blessed." Mindfulness	Experiencing the uplifts Spiritual awareness in practice and gratitude	Kame
		Caregiving was "overall . . . really, really . . . positive." "My childhood was extremely ordinary, which is perfect."	More "enlightened." "You think you do the right thing", but "you can't control" others' reactions. "This is the journey . . . my cross to bear and . . . testing ground . . . how we live our lives here will determine . . . the fate of our souls"	Grateful for present and past. Philosophical pondering Formal religion a source of learning and growth.	Elena

Application of Bowenian Family Systems Theory

Concept	Comments	Examples and Quotes	CG
Triangles "It just works better when the two of us" provide care.		D's father tried to pull her into a triangle with him and her brother to relieve anxiety from her brother's alcoholism.	Debbie
		When her sister refused to deal with their brother's pending death, D's husband became part of a triangle with her and her brother.	Debbie
		There was "conflict with myself . . . [and] with my parents." It was "was very, very stressful."	Jane
	Alone in caregiving without a triangle was unsustainable.	With her husband no longer co-caregiving, Debbie was "having to do it al. and planned end coresident caregiving.	Debbie
	Caregiving team as a functional triangle (Titelman, 1998): CGs coped with the stress of caregiving by bringing at least one other person into a caregiving triangle with them and their mother.	Husband and sisters, particularly one sister	Ann
		Husband: "It just works better when the two of us are around."	Debbie
		Sometimes daughters	Sarah
		Husband or friends	Penny
		Minimally daughter or brother	Jane
		Caregiving was "a shared thing" with her brother.	Elena
	Trust was key for the caregiving triangles to function well.	"really trust"	Ann
		Team "who I can trust and who I can rely on."	Elena
	Functional team improved relationship.	Caregiving "help[ed] me to understand him [brother] better".	Elena
	Triangulate neutral outsider	"Let a third party take over the finances."	Jane
Differentiation of Self "Attached at the hip"		For "one of the first times" Elena "actually . . . put up boundaries" with her sister, realizing her mother was not able to intervene.	Elena
	These CGs demonstrated sufficient differentiation to concern themselves with their mothers' well-being (Kerr & Bowen, 1988).	"It pleases me to know that she's taken care of and that she's well and that she's healthy."	Penny
		"Constantly working on . . . being more kind [and] being more patient" in order to "giv[e] her the best quality of life that she can have."	Jane
		Be "kinder and more patient" and "to be respectful and mindful of" her mother's needs.	Elena
	Identity and DOS were challenged by the constancy of caregiving.	She is "attached to me . . . more so than anybody else."	Sarah
		"I feel like I don't have my own life"	Penny
		"It's kind of like we're attached at the hip" "like when my daughter was little."	Jane
		"A bit of role reversal in that . . . she relies on me . . . emotionally more than anything."	Elena
Nuclear Family Emotional Process "Under the shadow of the family"	Antecedents in FoOs contributed to their caregiving frustrations (Keeling et al., 2008).	FoO was "dysfunctional", and her siblings were the "difficult part" of caregiving.	Debbie
		Penny was the responsible one growing up and in caregiving her "siblings do not help, at all."	Penny
		Penny "felt very unprotected" as a child and in caregiving, related to her FoO, "we don't have each other to depend upon".	Penny
		Jane's mother and stepfather "were both heavy drinkers."	Jane
		She discovered in caregiving and the preceding time of cutoff that with her stepsiblings she was not "close. . . it felt like it was all a lie."	Jane
		Trauma and loss were experienced by "everyone pretty much in my family" before Elena was born.	Elena
		"We all live in denial, and we don't communicate."	Sarah
Family Projection Process "It'll be my fault"	Mothers who projected onto the daughters who became CGs.	Growing up, Penny was responsible for housework and care of her siblings because her mother "always worked".	Penny
		Childhood responsibilities "definitely is where the caregiving started".	Jane
		"If my mother came home and the house wasn't clean, it was my fault." In caregiving if mother were to get hurt, "I'll never hear the end of it. It'll be my fault"	Penny
		Jane's childhood messages, "'Don't have any needs'", "Don't ever disagree'", and "I just can't . . . be real."	Jane
		Her mother when Jane was young once collapsed because "she was so exhausted", but also, "Everything revolved around her".	Jane

Application of Bowenian Family Systems Theory (continued)

Concept	Comments	Examples and Quotes	CG
Multigenerational Transmission Process Caregiving "changed my . . . ability . . . to interact with my kids"	Influence of past generations	"We didn't demand a lot from her", "I think because of her mom."	Ann
		Sarah was keeping her promise not to "put her in a home" because "her grandparents ended up in "not "a very nice place."	Sarah
	Generational influence on caregiving	Elena's mother's being "a good CG to" Elena's father "taught me patience, and . . . unconditional love and acceptance."	Elena
	Impact on next generations Dementia caregiving may alter interconnectedness in families. (Välimäki et al., 2012).	For Sarah's daughter the "transition shoulda been a little bit more . . . slow". Caregiving "changed my . . . ability . . . even to interact with my kids to some degree".	Sarah
		Her children "aren't always quite as understanding" and "I can't go see them".	Ann
Emotional Cutoff "The only way I could have a life of my own."	Potential to reignite problems that emotional cutoff made dormant but did not resolve.	With some geographical cutoff from siblings "We were able to keep it all together there till something happened to the parents."	Debbie
	Caregiving can be a bridge to overcome emotional cutoff. (Jacobs, 2015; Wuest et al., 2010)	Intentional with own children: "communicating more . . . I don't want them to . . . hide things from me. I want them to feel that I am here for them."	Ann
		"My relationship with my mom is the best it's ever been."	Jane
	For some there was evidence that cutoff from siblings enhanced their coping with caregiving and there were issues and cutoffs unresolved.	"If my brother were sober, um, we could have managed it better."	Debbie
		Dealing with siblings was "the difficult part."	Debbie
	Current cutoff	"The way she [sister] kind of behaves at times. . . I feel a little . . . an outsider."	Elena
		"None of us are really emotionally close" (siblings)	Penny
		No current interaction with stepsiblings and minimal help from brother.	Jane
	History of cutoff	"I felt free, so I ended up staying there", "the only way I could have a life of my own".	Penny
		A "huge fight" led to not "talk[ing] to them for two years." "It was pretty, pretty devastating."	Jane
	Emotional cutoff or part of the grief process?	"Not thinking of her as my mom"	Sarah
Sibling Position "I'm the oldest . . . she always thought I had to take responsibility"	Sibling rivalries and wanting to prove oneself as the better offspring have been noted to be a primary source of conflict in families dealing with parental dementia (Peisah, Brodaty, & Quadrio, 2006; Williams et al., 2016).	Penny's brother "could do no wrong" was "self-centered, self-righteous."	Penny
		"I stand up and I do the right thing." Her siblings "hate me for it and resent me for it."	Penny
		"good mom, good wife, good daughter"; "not so self-centered"; "the caretaker . . . the nurturer." "I did the right thing."	Penny
		Sister is "the most successful one out of all of us . . . with "perfect children." "I have a hard time understanding . . . my sister's behavior and I wish my mother could do a better job of, I don't know, explaining it."	Elena
	Children develop leadership tendencies and experience expectations to assume responsibility (BCFS, 2016f).	As the responsible one, "it's always been that way" and Debbie "ended up being the one" to provide care.	Debbie
		Debbie's sister adamantly deferred to her.	Debbie
		"Always the responsible one."	Penny
	The role of sibling position varied for these CGs. For the three not from a blended and therefore more complicated Foo. the oldest or oldest sister was the CG.	"I'm the oldest . . . she always thought I had to take responsibility anyway."	Ann
		Jane was the older of two until her mother remarried. As such, she was responsible for her father's care, the household, and her brother. She "was very parentified."	Jane
	Expectation of caregiving based on sibling position appears to be culturally specific (Pharr et al., 2014).	"In Latin America[n] . . . culture, uh, the youngest, . . . usually it's the youngest girl" is expected to care for parents.	Elena
Societal Emotional Process "My world has shrunk quite a bit."	Cutoff from the societal system	"My world has shrunk quite a bit."	Sarah
		"A very small, small world."	Sarah
		No report of centralized or systematized caregiving services	None
	Barriers to use of caregiving services	Medical need of CR	Sarah
		Finances	Jane

Table 4

Chart of Journal Data

Finding	Debbie	Ann
Idiosyncrasies		
Confirm	it drags on	Doesn't know I'm daughter
	Description of 6 years of caregiving	My children don't always
	aware of all dynamics and self-care	understand
Conflict	had a good relationship with both brother and sister, specifically before caregiving	
Person of mother		
Confirm	good relationship with my mother	She took care of her mom
	She was the one that was most patient, loving, and available.	Mom always a worrier
	Usually would listen and	
	tended to be more gracious in her responses to her children.	
	We had our spats,	
	She told me later I was always the independent one	
	When she was adamant, she was adamant.	
	personality is still the same . . . gentle, inquisitive, caring person, and adamant person	
	has not exhibited any anger or agitation	
New Information	she was adamant about not moving to a facility	
	want to help care for her	
Family of Origin		
Confirm	parents did not listen talk this out more with their children.	Family structure
	Family structure	just getting away and
	OK relationship with father; a better relationship later in life	making those plans [to get
	had a good relationship with . . . mother	away] can be a conflict
	husband and I have emotionally stable	
	Brother with substance abuse; brother's drinking escalated; We could have probably survived our spats and worked through it IF my brother had been in a better place	

New Information	Sister has struggled; My sister and I can usually work through our conflicts	
	My father was . . . mother's caretaker (multiple health issues) until multiple strokes lead to his death six years ago.	
	task then fell to the three children	
	which placed stress on [sibling] relationships	
	leading us to move in to take care of Mother	
	Description of 6 years of caregiving - from family perspective	
	[Brother] died. My husband and I were left to take care of his estate.	
	My sister and I still have a fairly decent working relationship	
	Told my husband once that I am not sure I want a relationship with her after this is all over	
	I am finding "family" to be unhelpful and a drain on my life.	
	did not bargain for ALL of what I got with my family.	
	Taking care of Mother has placed stress on my relationship with my siblings	
	[brother 2 years older]	
	[sister 8 years younger]	
	Sister with [mental health issues]	
	Mother could never acknowledge or accept our weaknesses of failings	
	I find myself less inclined to "care" about [sister's] life	
	[Caregiving] has changed our long-term relationship	
Dialectics Confirm		Up-and-down experience
Loss of Freedom Confirm	wings have been clipped.	Have to plan ahead to do things
	had the freedom	Everything takes longer.
	vocational	Meals
	go and do as we please.	Can't leave her alone
	vocational changes.	Showering
	meals [for mother] versus just eating on our time schedule	Cleaning
		TV watching
		Hard to plan
		Privacy in our home

Accepting, adjusting, adapting		
Confirm	Adjusting continually re-evaluate my strategies day to day adjustment what life changes cause me/us to have to rethink strategies?	
Role reversal		
Confirm		Like caring for a child.
Decision to care		
Confirm	She told me later I was always the independent one	
Help		
Confirm	In the beginning, we three tried to work together to care for her If [brother] had been clean and sober and in counseling, I think we could have managed and cooperated for a longer period of time Prepping the day for any caregivers	right now, working pretty well one sister still works fulltime
New Information	Making sure I am . . . back at the time the caregivers need to leave answer questions or problems as they come for caregivers	
Repetition		
Confirm	Constantly repeating myself and answering the same questions over and over and over again	
Doing the best I can		
New Information	Figuring out how best to keep her occupied on things she enjoys.	
Mental health needs, emotional, spiritual		
Confirm	bitching at God more God can take it. honest dialogue with God.	Sad Not how we saw retirement Lost prayer warrior
Conflict	I hate the caregiving role	Sometimes angry
New Information	I am pissed less willing and more resentful always had moments of depression and anxiety when life gets overwhelming difference . . . it is more prominent (pops up more and last longer).	Sometimes angry Don't understand

Meaning	focus more on finding joy in my life	Knowing this is what I am
Confirm	it will help make me a better pastor and counselor	here for right now
	this will not last forever	Moved here 4 years ago
		Focus more on finding joy
New Information		in my life
Learning		
Confirm	I am also learning how it is really a day to day adjustment	

Table 5

Raw Quantitative Data

	ZBI		PHQ-8		PBI		FMTC				LSRS								RMBC												
	PS	Tot	Dif	Tot	PBI-C	PBI-O	LP	PM	UM	Tot	AA	AB	AC	CA	CB	CC	Tot-A Tot-C	Tot	Mem			Dis			Dep			Tot		
																			P	AR	TR	P	AR	TR	P	AR	TR	P	AR	TR
Ann	21ª	28ª	N	6ª	19ª	7ª	45	73	25	143	35	25	25	20	35	10	85/65	150	6	2.3	14ª	2	1	2	1	1	1	9	1.9	17
Debbie	25ª	30ª	S	7ª	29	17	35	60	16*	111ª	15	15	25	35	10	25	55/70	125ab	6	1.7	10	2	2	4	4	1.3	5	12	1.6	19
Sarah	21ª	26ª	S	9ª	32	7	41	70	20	131	35	5	25	30	5	15	65/50	115ª	7	.29	2	3	2.7	8	2	4	8	12	1.5	18
Penny	21ª	23	S	2	18ª	12ª	54	82	21	157	5	10	0	30	10	0	15/40	55ª	6	1	6	3	2.3	7	3	1.7	5	12	1.5	18
Elena	7	10	N	2	31	9	78	85	25	188	10	0	10	20	0	5	30/25	55ab	2	.5	1	0	0	0	1	2	2	3	1	3

All: Tot = Total
* out of 20. Did not complete 1 question.
ªabove average or cutoff
ᵇlarge age difference between siblings

ZBI = Zarit Burden Interview; PS = Personal strain

PHQ-8 = Patient Health Questionnaire-8; Diff = Difficulty; N = Not difficult at all; S = Somewhat difficult; V = Very difficult; E = Extremely difficult

PBI = The Parental Bonding Instrument; PBI-C = Care sub score; PBI-O = overprotection sub score

FMTC = Finding Meaning Through Caregiving scale; LP =Loss/Powerlessness subscale; PM = Provisional Meaning subscale; UM = Ultimate Meaning subscale

LSRS = Lifespan Sibling Relationship Scale; AA = Adult Affect; AB = Adult Behavior; AC = Adult Cognition; CA = Child Affect; CB = Child Behavior; CC = Child Cognition; Tot-A = Total Adult; Tot-C = Total Child

RMBC = Revised Memory and Behavior Problems Checklist ; Mem =Memory; Dep = Depression; Dis = Disruptive; P = Problems; AR = Average Reactions; TR = Total Reaction

Zarit Burden Interview, (Zarit, 2018)	25th quartile	50th quartile	75th quartile	Total score	Cutoff score	Personal strain (PS): Personal strain, a predictor of psychological distress in dementia CGs was defined as "the caregiver's subjective and emotional responses to a range of aspects of caregiving" (Branger, O'Connell, & Morgan, 2016, p. 502)
Measure of CGB	3	9	17	Range 0-48	24-26	Items 1-10 of 12 items Range 0-36
	(Bédard et al., 2001)					Research using the 22-item ZBI (Harding et al., 2015), which has 12 items for the measure of PS (Mapi Research Trust & Zarit, 2017), provided a score at the top of the 3rd quartile for a group of dementia CGs (Harding et al., 2015). Adjusting for the 10 personal strain items in the 12-item ZBI, the upper quartile would begin at a score of 18.3. While no specific cutoff is provided for PS, this gives insight into severity of PS.

Patient Health Questionnaire-8 (PHQ-8) (Kroenke & Spitzer, 2002)	Depression Severity Cutoff scores		Total score	Difficulty			
Depression screening tool	5 - mild depression		Range 0-24	Individual checks 1 of 4 options describing how difficult the problems they scored, regarding work, home and dealing with others			
	10 - moderate depression						
	15-moderately severe depression			Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult

The Parental Bonding Instrument (PBI)) (Parker, Tupling, & Brown, 1979)	Care sub score Cutoff = 19 Range = 0 - 36		Overprotection sub score Cutoff = 7 Range = 0 - 39		"'affectionate constraint' = high care and high protection"*	"'affectionless control' = high protection and low care"*
	Low	0-26	Low	0 - 13.4	"'optimal parenting' = high care and low protection"*	"'neglectful parenting' = low care and low protection"*
	High	27-36	High	13.5 - 39		

*(Parker et al., 1979, p. 2)

Finding Meaning Through Caregiving scale (FMTC) (Farran, Miller, Kaufman, Donner, & Fogg, 1999a).	Loss/Powerlessness subscale	Provisional Meaning subscale	Ultimate meaning subscale	Total meaning
Number of items	19	19	5	43
Range	19-95 (reverse scored)	19-95	5-25	43-215
	Challenging facets of caregiving	How CGs find day-to-day meaning	Reflects Frankl's (2000) construct: philosophical, spiritual, religious meaning	

Lifespan Sibling Relationship Scale (Riggio, 2000)		Adult	Child	Total A + C	In research on the LSRS, an average total score of:
	Affect	0 - 40 (AA)	0 - 40 (CA)	-------------	178.5 corresponded with the most positive sibling relationships
	Behavior	0 - 40 (AB)	0 - 40 (CB)	-------------	140.3 corresponded with the most negative sibling relationships
	Cognition	0 - 40 (AC)	0 - 40 (CC)	-------------	35.07 was the highest subscale
	Total A = B = C	0 - 120 (Tot-A)	0 - 120 (Tot-C)	0 - 240	

Revised Memory and Behavior Problems Checklist (RMBC) (APA, 2018; Teri et al., 1992) A subjective measure of the CGs experience of CR behavior problems and associated burden in the CG (Roth et al., 2003). For each problem, CG indicate whether it occurred and how much it bothered them on a Likert scale 0 (not at all) to 4 (extremely)	Subscales	Problems	Average Reactions	Total Reaction
	Memory 7 problems	# of memory related problems that occurred in past week	Total Reaction divided by the # of problems	Sum of Likert scores for the problems that occurred Range 0 - 28
	Disruptive 8 problems	# of disruptive behavior problems that occurred in past week	Total Reaction divided by the # of problems	Sum of Likert scores for the problems that occurred Range 0 - 32
	Depression 9 problems	# of depression related problems that occurred in past week	Total Reaction divided by the # of problems	Sum of Likert scores for the problems that occurred Range 0 - 36
	Total scale	Total # of problems that occurred in past week	Total Reaction divided by the total # of problems	Sum of Likert scores for all problems that occurred Range 0 - 96

Table 6

Triangulation of Quantitative Data with Findings

	Elevated scores	Discussion	Notable scores	Discussion
ZBI - PS	D- 25	D's high score here corresponds with her observed level of psychological distress related to caregiving	E - 7	E's score was well below the cutoff. This reflects her low level of psychological distress observed in caregiving itself.
	A, S, P - 21	In the analysis, these three CGs were noted to feel "depleted," "overwhelmed," "drained" by the constancy of caregiving. It thus fits that their Personal Strain scores are elevated.		
ZBI - Total	D - 30	D's sense of burden in her caregiving situation was clear in her analysis and confirmed by this score.	P - 23 E- 10	P and E were both caring for mothers who were less cognitively impaired than the other CGs. That was particularly so for E who was also no longer coresident, consistent with her very low ZBI score
	A - 28	A's emphasis on the constancy of caregiving fits with her high ZBI score		
	S - 26	S's feeling "depleted" and like she had competing demands also fits with her elevated ZBI score.		
PHQ-8	S - 9	S found it "really hard to stay positive." Her analysis references her feeling sad and "depleted," fitting with her having the most elevated PHQ-8 score		Findings are consistent with these scores for possible mild depression. That is particularly fitting to the concept of Ok, but not thriving.
	D - 7	D's analysis included stating "it's not a horrible life," dissatisfaction with her situation, and awareness she was more depressed, supporting the PHQ-8 elevation.		
	A - 6	A emphasized her sadness at loss of related to her mother and the reality that dementia is "gonna get worse," in keeping with her PHQ-8 score.		
FMTC	D - 111	D was the only CG to score below the cutoff on the FMTC, which fits with her strong statements indicating she disliked solo caregiving and was ready to end coresident caregiving.	E - 188	E's particularly high FMTC score may be related to her mother's being very early in the dementia process, her no longer being coresident, her frequently referenced faith (although that was not unique among these CGs), cultural differences, her working fulltime - a potential source of additional meaning, or an unobserved factor. This does fit frequent references in the analysis to her having done work on meaning-making.

	Elevated scores	Discussion	Notable scores	Discussion
LSRS	D - 125	D's LSRS score is below the cutoff for negative sibling relationships and her analysis strongly reflects that negativity. The score would have been lower except that it is influenced by higher subscale scores for childhood affect and cognitions. That she had better relationships with her siblings in childhood is confirmed in D's journal and was not observed in the analysis.	A - 150	A was noted in the analysis to have a uniquely harmonious relationship with her siblings. That only she was above the cutoff for negative sibling relationships on this measure closely fits that portrayal.
	S - 115	S's conflict with her siblings was not overt in the analysis, yet this score is lower than D's. This could be due to geographic distance, her being the only sister, the passive way in which caregiving was thrust on her, or an unobserved finding. The score reflects a lack of closeness but does not fit with the observed lack of conflict in her sibling relationships.		
	P, E - 55	P's and E's scores are very low reflecting the analysis depiction of conflict in their sibling relationships		
RMBC Memory problems - Total Reaction	A - 14	The only elevated score on the RMBC, reflects A's sense of being bothered by her mother's memory related problems.	D - 10	D's score is slightly below the mean (11.12) on this measure. That is surprising considering that the analysis observed her being bothered by her mother's repetitiveness.
			S - 2	More surprising was S's score, which was very low. The analysis or S reflects less bothersomeness related to repetition that for D, but it clearly shows she was found it bothersome.
				Thus, in the analysis, the statement that the CGs "found the repetitiveness of dementia caregiving bothersome" is only partially supported here.
				No CR was noted to have significant behavior problems, supported by the fact that only 1 of 60 RMBC scores was elevated.

PBI
Rather than a cutoff or mean score, the PBI provides a descriptive result based on the Caring and Overprotection subscales. The participants are placed in the appropriate box below based on their scores.

"'affectionate constraint' = high care and high protection" *	"'affectionless control' = high protection and low care" *
D - 29/17 D 's analysis demonstrated fondness for her mother and a statement that she was "very easy to get along with", supporting the affectionate portion of this measure. There was little discussion of her childhood and nothing observed in the analysis suggesting high protection/constraint. Neither confirming not disconfirming any particular data.	
"'optimal parenting' = high care and low protection" * S - 32/7 S did not discuss much of her childhood, but her descriptions of her mother were positive and warm, confirming this score. An interesting observation is that S's analysis most strongly reflected on possible reverse attachment. If indeed her mother provided optimal parenting, it would have impacted their original attachment relationship. While not a strong confirmation of the concept of reverse attachment this score nonetheless is supportive. E - 31/9 Despite E's sibling conflicts and frustration that her mother was not intervening for her with her sister, E spoke only positively about her mother, evidenced warmth toward her, and spoke strongly of having an optimal childhood. Thus, this score is confirming of the data.	"'neglectful parenting' = low care and low protection" * A - 19/7 There was nothing observed in A's story that would suggest she thought her mother was a neglectful parent. However, the analysis does show that her mother was very busy in A's childhood. A could not "demand a lot from her," and she readily "moved me on." That analysis thus reflects her PBI score. P - 18/12 This score fits Penny's story of a conflicted relationship with her mother, not having her mother's support or protection from her father in childhood, and having to be in charge of the household,

*(Parker et al., 1979, p. 2)

Figure 1. Potential triangles that may occur for dementia caregiving dyads. The blue conjoined circles represent the CG and CR. While there are likely positive and negative experiences between them. The black minus signs represent time of greater negativity in the relationship. According to Bowenian theory, such stressful times may precipitate pulling in a third party to dissipate the tension. That third party may be:

- An immediate family member, represented by the red circles
- A member of the family system, represented by the green circle, outside the immediate family
- A member of the caregiving system represented by the oval black circle This could be someone like a

   doctor or a case worker.

- A member of the societal system, represented by the largest, black circle. It could be someone proximal

   like a friend or neighbor, or someone distal, such as a public policy maker.

The stressors of caregiving may also lead to triangulation of the CG with immediate family
      members, without the

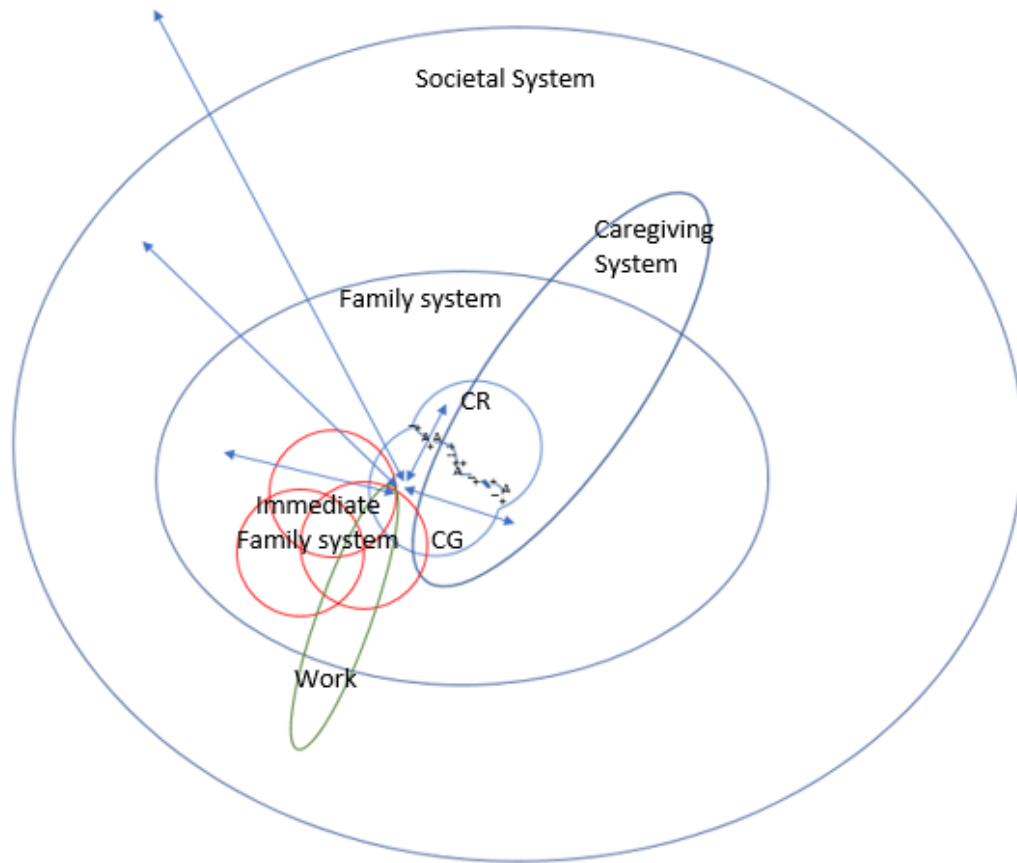CR, this is represented by the red triangle with dashes.

Figure 2. Offspring dementia caregiver milieu. In the caregiving dyad, there is a permeable, changing boundary that reflects the positive (+), negative (-) and ambivalent (A) aspects of the experience and the relationship. The arrows represent the two-way interaction of the CG, striving to find meaning in the dyadic relationship, the family system, the societal system and, transcendently, beyond those systems. Offspring CGs likely have multiple relationships and triads within the immediate family system (red circles) and work or other nonfamilial responsibilities (green oval), sources of additional burden or meaning. For simplicity, additional two-ways arrows are not drawn, but the complexity of the offspring CG milieu is clear. Engagement in life and finding meaning are important aspects of well-being. Offspring CGs have multiple sources beyond the caregiving dyad to become engaged and from which to find meaning.
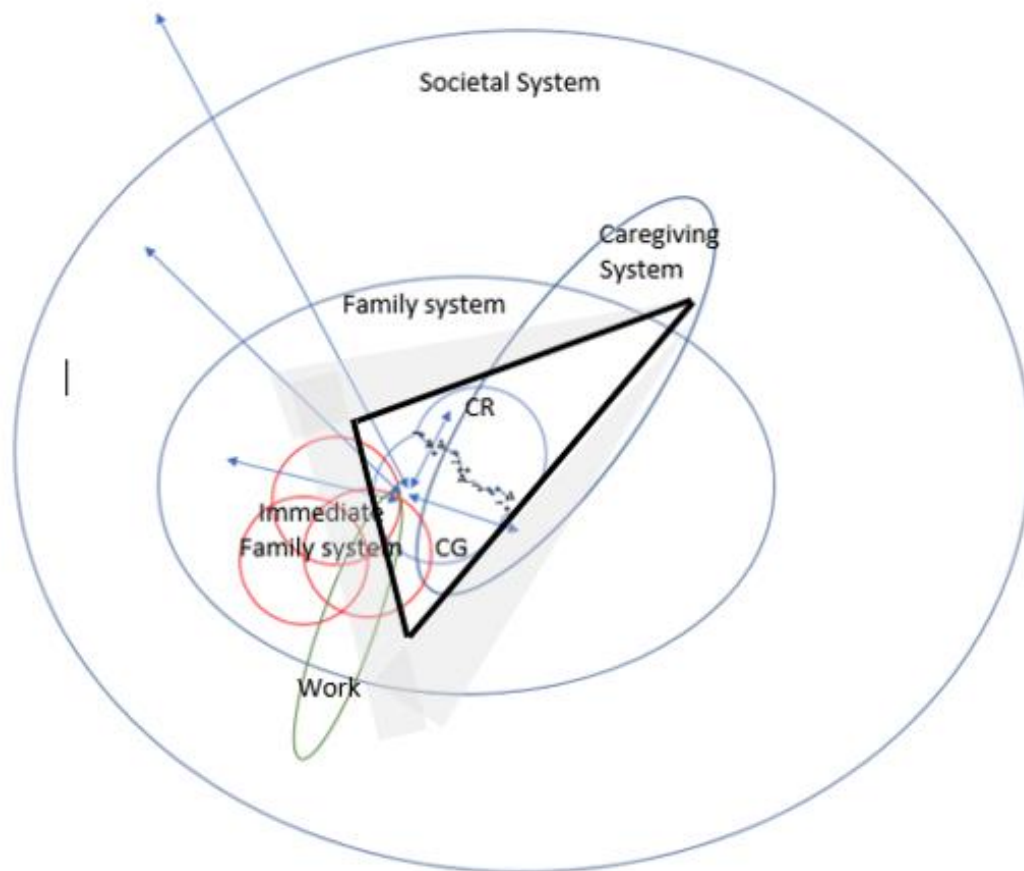
Figure 3. The dementia care triad (△) is a theoretical alternative to addressing care and research for a CG-CR dichotomy and incorporates member(s) of the formal caregiving system (Adams & Gardiner, 2005). It can easily expand (   ) to include multiple members of the Family and caregiving system (Adams & Gardiner, 2005).
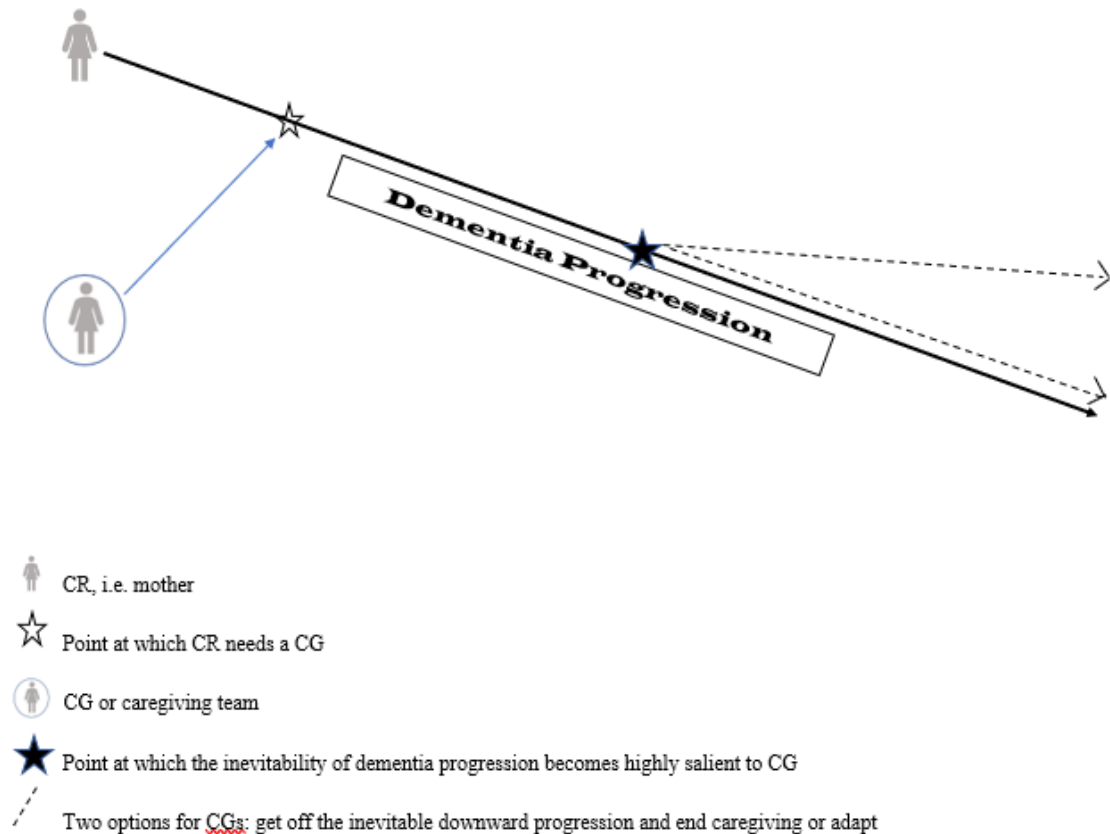
CR, i.e. mother

Point at which CR needs a CG

CG or caregiving team

Point at which the inevitability of dementia progression becomes highly salient to CG

Two options for CGs: get off the inevitable downward progression and end caregiving or adapt

Figure 4. This figure represents Ann's experience with caregiving demonstrating with the solid black arrow the inevitability of her mother's dementia progression. At the point when she began caregiving, represented by the open star, Ann, and later her caregiving team, joined her mother's downward progression. Within the caregiving experience there are times when the inevitability of dementia progression becomes highly salient to the caregiver. It likely occurs at multiple times, perhaps even continuously, but for parsimony, that o and in some ways those times are represented by one filled star. Because the dementia progression will not stop, as Ann noted, "that's a progression and I know that's gonna get worse," there are not many options at those times. One option is to separate from the downward progression via discontinuing caregiving, represented by the higher dotted arrow. The other is to adapt, represented by the dotted arrow parallel to the dementia progression. Ann and her caregiving team have chosen to adapt.
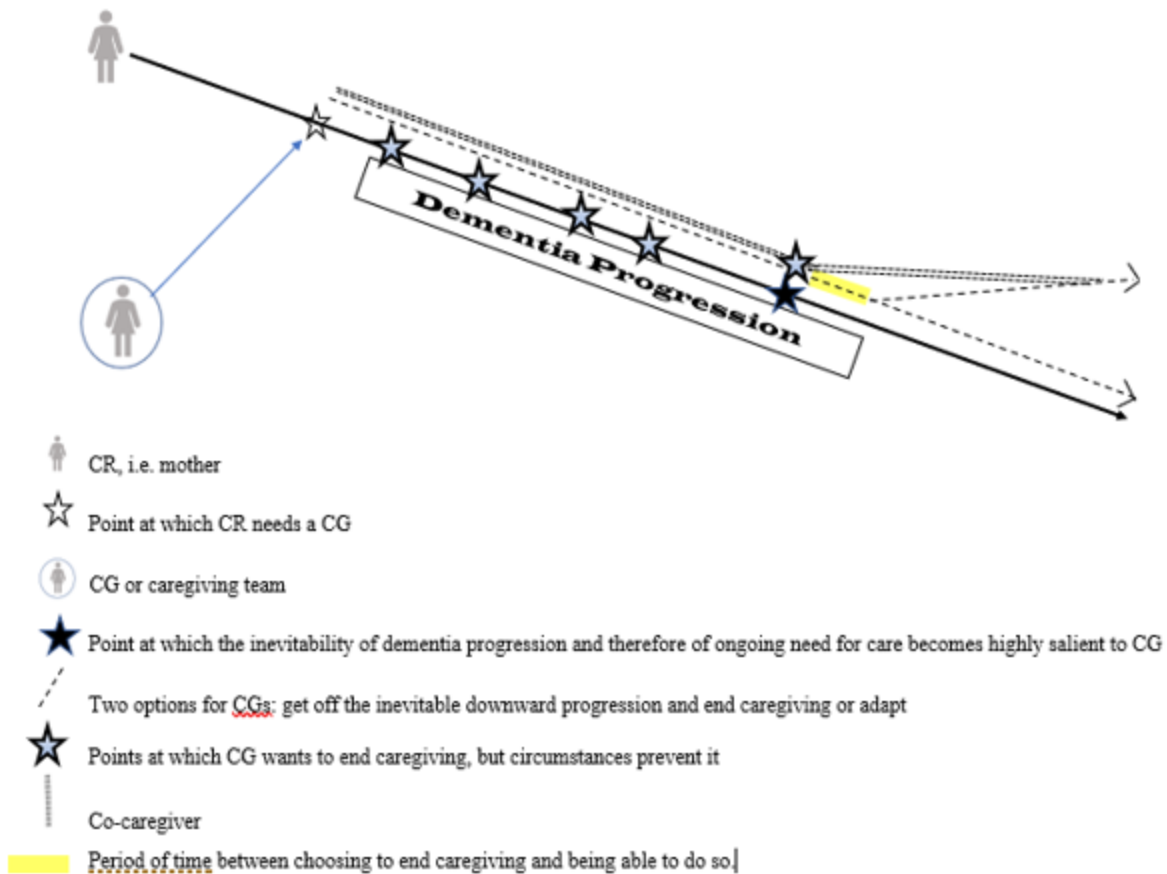
CR, i.e. mother

Point at which CR needs a CG

CG or caregiving team

Point at which the inevitability of dementia progression and therefore of ongoing need for care becomes highly salient to CG

Two options for CGs: get off the inevitable downward progression and end caregiving or adapt

Points at which CG wants to end caregiving, but circumstances prevent it

Co-caregiver

Period of time between choosing to end caregiving and being able to do so.

Figure 5. This figure represents Debbie's experience with caregiving. The solid black arrow demonstrates both the inevitability of her mother's dementia progression and subsequent need for care. At the point when she began caregiving, represented by the open star, Debbie and her husband joined her mother's downward progression. Debbie experienced multiple times, represented by the dark outlined stars, when she expected to end caregiving but was prevented by circumstances. She has come to the time, represented by the filled star when the inevitability of dementia progression and need for care has become so highly salient, related to her husband no longer being able to be a co-caregiver, that she is planning on ending caregiving. The dotted line represents her caregiving journey and her choice to join her husband and discontinue caregiving. He is represented by the double line, having paralleled with her caregiving until he could no longer do so at the solid star.