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2018

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UNIVERSITY OF CALIFORNIA
Los Angeles

Off-time life-course Caregiving:
“The Experience of Early-onset Dementia
on Spousal Caregivers”

A dissertation submitted in partial satisfaction of the
requirements of the degree Doctor of Philosophy
in Public Health

by

Elvira Elizabeth Jimenez

2018

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ABSTRACT OF THE DISSERTATION

Off-time life-course Caregiving:
“The Experience of Early-onset Dementia
on Spousal Caregivers”

by

Elvira Elizabeth Jimenez

Doctor of Philosophy in Public Health

University of California, Los Angeles, 2018

Professor Steven P. Wallace, Chair

Dementia, once assumed to be only a disorder of the very old, is increasingly diagnosed in individuals under age 65. Those with early-onset dementias (EOD) present unique challenges to both individual families and society. The presence of this illness initiates an unexpected and unplanned caregiving situation for families; in EOD it is primarily the spouses who assume the bulk of the caregiver responsibilities. EOD caregivers may face distinct factors that shape their caregiving experience. Moreover, it is a relatively unstudied situation and little is known of its impact on the emotional status of caregivers.

This caregiver study used a qualitative grounded theory approach. It reports on 29 spousal caregivers and their corresponding care-recipient. The study was conducted as part of a parent study that compared care-recipients afflicted with two predominant EOD subtypes: behavioral variant Frontotemporal dementia (bvFTD), which displayed primarily behavioral and

social disturbances, and early-onset Alzheimer’s disease (EOAD) with cognitive decline.

Employing thematic analysis, it describes the caregiver perspective of the illness trajectory. Emerging themes include “the illness process,” the “care-recipient’s symptomology,” and the actions involved in EOD caregiving. The emerging categories include “caregiver illness-related tasks,” “non-caregiving-related tasks,” and “emotional reaction to tasks.” It also found temporality issues specific to EOD caregiving such as “life-course stage” and “off-time” themes. It proposes an EOD caregiver trajectory. Lastly, it presents two major grief-related categories—anticipatory and concurrent grief—and proposes an EOD grief model. It also describes the care-recipients’ disease and caregivers’ emotional outcomes utilizing demographic and survey data.

This study provides a glimpse of these caregivers’ lived experience. It places the caregiving tasks and the illness within the context of their everyday realities. Additionally, it exposes the emotion underlying their caregiving experience as well as the lack of resources available to them. The knowledge of the underpinnings of EOD caregiving presented in this study will both increase awareness and help focus service provision and policies within the EOD dementia caregiving. This study finds that EOD caregivers are individuals that traverse this part of their life with an enormous and complex burden—they are truly besieged individuals.

The dissertation of Elvira Elizabeth Jimenez is approved.

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2018

Dedication Page

Este trabajo lo dedico a ti Héctor, que eres el amor de mi vida y mi eterno compañero. Este trabajo lo comencé a tu lado y tristemente lo completé en tu ausencia. Nuestro propio camino marca esta investigación ya que al permitirme compartir tu enfermedad me dio la habilidad de entender con profundidad el amor, esfuerzo, angustia, dolor, cercanía y satisfacciones que trae asistir a un ser querido— cada cuidado es una verdadera expresión de amor. Con la conclusión de este trabajo doy fruto a nuestras largas noches en el hospital y en casa, sorprendentemente incluso durante esos momentos difíciles continuamos construyendo nuestra vida juntos y consolidando nuestra conexión—leyendo, comiendo, charlando, escuchando música, calmando tu fiebre, tus malestares, llorando, riendo o simplemente compartiendo el momento. Todo eso fue una parte significativa de nuestra vida junta—tu contabas conmigo y yo contaba contigo. Que alegría y que afortunada el saber que he podido contar contigo—ya sabes no hasta 2, 3, o 15...sino eternamente—tu mi lindo compañero siempre podrás contar conmigo. Héctor Rolando Rivera— ¡Presente!

Les dedico este trabajo también a mis padres, Elvira A. Rodríguez y Rubén Rodríguez. Se lo dedico a usted mamá, por su constante e incondicional apoyo y amor. Y es por usted que he conocido lo que es la fortaleza y persistencia en la vida. Mamá usted ha sido una constante guerrera y por usted aprendí a ser una también —su lección contante es que “todo lo que uno se propone es posible”. Ya que usted tuvo la fortaleza y coraje de emprender ese viaje es que puedo llegar a este momento y disfruto de este logro— un fruto más es su abundante cosecha. Se lo dedico a usted papá, mi primer maestro, que me enseñó a usar mi voz, tener curiosidad a la vida y forjar mis propias ideas. Gracias papá por años de discusiones sobre la política, religión, la vida, naturaleza, etc. Papá somos tan afortunados que usted es parte de nuestra vida— tuvimos una segunda oportunidad por usted. Mis queridos padres gracias por quererme tanto—los adoro. ¡Mamá y Papá lo logramos!

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Acknowledgements

This work would not have been possible without the help of UCLA professor, Dr. Mario Mendez and his grant from the National Institute of Aging (5R01AG034499). Dr. Mendez generously shared the data from this study and provided resources to collect the caregiver interviews. Additionally, he mentored and supported me throughout this doctoral process and research career. Mario, thank you, I feel fortunate to have worked alongside you for all these years. Your mentoring and guidance has been key in my research career—most important to me is your invaluable friendship.

This work was also possible due to the guidance and contribution of my doctoral committee. I am especially grateful to Dr. Steven P. Wallace, my doctoral committee chair, who has believed, guided, and supported me every step of the way. Dr. Wallace, I feel privileged to be your mentee—thank you for the long hours of guidance as I developed this work and discover my niche. I would also like to acknowledge Jill Shapira, RN, PhD, whom I consider my sixth unofficial committee member. Jill Shapira generously shared her expertise with this important caregiver population—and nurtured my understanding in this field. I am so indebted for her contribution and joyful for her friendship.

I would like to also recognize those who have advised and supported my academic Journey. First, Dr. Lissy Jarvik, MD, PhD, under her mentoring I initiated my work in the dementia discipline. I feel grateful to have been mentored by such a pioneer in the field of ageing. I have had amazing role models, such as Cynthia Mojica, PhD, MPH, and Gina Wilson-Ramirez, MD, who paved the way and encouraged me throughout this path. My classmates—Parichart Sabado, PhD and Soultana Haftoglou, PhD—whom I am proud to be one of the three musketeers, we supported each other throughout our course work. My neuro-behavior family who helped with the project and the preparation of this dissertation, Diana Chavez, Michelle Mather, and Randy Desarzant. To Maureen Jerrett who provided invaluable editorial assistance.

Lastly, I want to acknowledge the lifelong support of my family. I thank my mother and father who created the supporting and loving family that allowed me the liberty to pursue my dreams. Hector, the love of my life, and whom I lost in this journey, even in his absence he continues to encourage me. My siblings—Amilcar, Italo, and Loly—who have been my forever partners in life—their belief in me helped nurture my dreams and pushed me to accomplish them. I thank my nephews and nieces—Sarita, Sofia, Jose Amilcar, Marco, Lucca, and Camilo—who inspired me to break barriers so that that their dreams can be even grander. I am so proud of being part of this first-generation immigrant *Salvadoreña* family who is a true example of the legacy of our people—*el pueblo Salvadoreño, mi first love*.

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Caregiver Burden in Frontotemporal Dementia Compared to Early-Onset Alzheimer's Disease". 143rd APHA Annual Meeting and Exposition (335841) Chicago, Illinois- Oral Presentation. Elvira Jimenez, Jill Shapira, Fernando M. Torres-Gil, Steven P. Wallace, Li-Jung Liang, Michelle Mather, Mario Mendez.

Chapter 1: Introduction/Background

Introduction

Research Question

Early-onset dementia (EOD) strikes patients and consequently their caregivers at an unexpected time in their life-course, displacing every aspect of their lives. EOD refers to any dementia that has an onset before the age of 65 years. The EOD situation is an unexplored and an unexpected occurrence. It is an important topic dealing with a distinct dementia condition of a population that is not easily accessible for most researchers. Furthermore, caregiving to this population offers its own peculiarities and has been explored even less as the limited research in this area has been focused at understanding the disease—increasing and understanding of the EOD caregiving experience and its consequences is essential not only for caregivers but also the dementia community.

EOD caregivers, regarded as the “invisible patient[s]” carry the brunt of the care and are subjected to substantial stress, burden, and distress (Roche, 2009). The individual’s experience of EOD caregiving is shaped not only by factors associated with the caregiver role, but also by the linkages of this role with the realities of everyday life, life-course stage, and social-cultural background. Caregiving in general entails substantial emotional and physical distress that adds burden and strain to a family unit that already may be facing its share of common life stressors. While much is known about caregiving to those with dementias at an older age, the needs and issues of cognitively impaired younger adults have yet to be addressed. Additionally, dementia caregiving itself is not a static situation, but it evolves as the disease progresses. This study explores a major question: What is the experience of caregivers who are looking after someone with an EOD?

The following specific aims will be explored:

- i. How do spousal caregivers of those with EOD describe their caregiving experiences, challenges, and rewards? The goal of Aim 1 is to better understand how the uniqueness of this illness contributes to the overall caregiver experience.
- ii. How does the “life-course stage” of EOD caregivers and care-recipients affect the caregiving experience? Aim 2 characterizes caregiving for this rare form of dementia as experienced within temporal and contextual considerations. It accounts for the “life context” of caregivers through an exploration of the individual as well as the family unit (micro level) embedded within the social context (macro level).
- iii. How does the caregiving experience influence the emotional status of caregivers? Aim 3 addresses components that contribute to the emotional consequences of EOD caregiving.

Background

Most of our knowledge of EOD caregiving derives from general family caregiving concepts (i.e., non-specified caregiving applicable to most caregiving situations) and the broader dementia caregiver research as described below. Caregiving is a broad term that includes everything from routine everyday “care” exchanges to chronic disease situations; it involves caregiving to a wide range of populations including children, disabled adults, and the elderly. First, I review the literature on family caregiving to identify commonalities across caregiving groups that may also affect EOD caregivers. Second, I examine dementia caregiving research, highlighting dominant issues affecting caregivers of unspecified dementias—mainly dementia with late-onset individuals. Lastly, I summarize the literature on dementia caregivers who provide care for individuals diagnosed with EOD before age 65. The aim is to assess EOD family caregiving from a broad to a more focused perspective to describe what is known about this study population.

Nonspecific Family Caregiving

Caregiving is the common act of caring and providing support or assistance to a loved one in need. According to Abel (1990), caregiving is an essential human activity with the “ability to sustain life, nurture the weak and respond to the needs of the intimates” (page 4). As human beings we rely on an array of social exchanges; caregiving is one of these necessary social exchanges for many people—not everyone. It is a service that helps sustain society; we have caregiving responsibilities throughout our life-course, and it is an experience of all humanity (Talley et al., 2012). In this study, I will focus on informal, unpaid spousal caregivers of impaired adults who acquired the illness of dementia before age 65. Below I discuss (1) what family caregiving is and how it is defined, (2) why family caregiving is an important issue, and

(3) who provides family caregiving.

Family caregiving is different from the daily reciprocal exchanges between individuals. It refers to the situation when normative social exchanges become unilateral and obligatory due to illness or age-related frailty, resulting in an alteration of the prior established relationship (Abel & Nelson, 1990). At this point, the relationship and expectations become one of caregiver and care-recipient. Informal caregiving occurs in domestic private settings and is unpaid (Abel & Nelson, 1990). However, it is often unclear when a person becomes a family caregiver because there is no delineation between what is a normative healthy exchange of aid and the more demanding family caregiving associated with illness. Moreover, there is a bias towards normalizing or maintaining family caregiving as a “normal” social expectation or an extension of interpersonal relationships. However, at some point, the role of “family caregiver” is attained where a significant responsibility for an impaired relative is assumed, involving much more than a minimal increase of assistance. Furthermore, caregiving becomes a public health concern when the interchange of assistance, increased demands, and the absence of supportive networks and services overpower caregivers (Pearlin et al., 1990). Under circumstances of illness, caregiving demands may take over most aspects of the caregiver’s life, forcing them to restructure their existence to accommodate the needs of the care-recipient.

There is no concise definition of informal family caregiving since assistance to a loved one is seen as an established activity in normal, everyday social interactions (Barer et al., 1990; Cantor, 1991; MaloneBeach et al., 1991; Roth et al., 2015; Walker et al., 1995). Caregiving is often defined as people who help impaired relatives or friends carry out functional and instrumental activities of daily living (Abel, 1991). In addition, family caregiving is often quantified by the number, type, and intensity of tasks carried out by caregivers. However,

caregiving and its activities are not detached from emotion; these actions are embedded within an intimate personal relationship; yet, emotional aspects are often not addressed (Abel, 1991).

Thus, to better capture the impact of caregiving in families, it is important to recognize both caregiver specific tasks and the emotional consequences of caregiving (Graham, 1983).

Impact of Nonspecific Family Caregiving

Family caregiving, considering changes in the labor market and healthcare structure, is a significant issue and is becoming an increasing concern mostly in older people's lives. Currently, aging of the baby boom generation and the increased cost of long-term care have reduced access to the formal caregiver sector and forced an even higher reliance on informal caregiving.

According to the American Association of Retired People (AARP) in 2013 about 40 million people in the United States provided informal care to an adult with some level of impairment; they provided up to 37 billion hours of care at an estimated value of \$470 billion (Reinhard et al., 2015)— which is greater than the \$339 billion paid for formal long-term care (Colello et al., 2015). The aging of the baby boom cohort signifies an even greater caregiving demand at a time when the number of caregivers is projected to decrease (Redfoot et al., 2013). This is also a relevant issue to EOD caregivers because they may be concurrently caring for multiple family members (Gibson et al., 2014).

Consequences of Family Caregiving

Family caregiving is also an important issue because of its myriad effects on caregivers. Caregiving may have mental health consequences such as depression, anxiety, and stress overload (M. Pinguart et al., 2003; Schulz et al., 2008), as well as poorer physical health and higher mortality (Martin Pinguart et al., 2003; Schulz et al., 1999) compared to non-caregivers. However, caregiving can also be positive, as altruistic acts make individuals feel good by adding

meaning to their lives and strengthening family relationships (Schulz & Sherwood, 2008) (Roth et al., 2015).

Caregiver research has proliferated in multiple disciplines. However, the detrimental effects of caregiving persist—primarily stress and burden—as the dominant focus in the literature. The main hypothesis is that caregiving is a highly burdensome role that results in increased stress and jeopardizes the caregiver’s physical and/or psychological health (Zarit et al., 1980). Caregiving psychological stress may surpass the individual’s coping capabilities. Psychological stress is a result of the individual’s interaction with the environment as evaluated by the individual, at the point when the demands exceed coping capabilities (Folkman et al., 1986; Lazarus, 1974, 2000). However, currently, there is literature reassessing the high prevalence of detrimental physical and psychological outcomes that have been traditionally been reported (Roth et al., 2015).

Additionally, the physical health of the caregiver may be compromised as a consequence of stress, either through direct physiological alterations or by encouraging unhealthy behaviors (Schulz et al., 1995; Schulz & Sherwood, 2008; Shaw et al., 1997). Physiologically, prolonged exposure to stress results in alterations of sympathetic arousal and cardiovascular reactivity, which in turn leads to increased cardiac risk and decreased immune response, predisposing caregivers to cardiovascular disease, hypertension, and infections (Schulz & Sherwood, 2008). Additionally, caregiver distress and burden may encourage unhealthy behaviors such as decreased exercise, unhealthy eating habits, non-compliance with healthcare, and tobacco and substance abuse (Vitaliano et al., 2003). However, specific findings of the negative physical effects of caregiving cannot be fully explained (Harmell et al., 2011; Schoenmakers et al., 2010; Walker et al., 1995).

There are several contextual factors that contribute to the psychological distress reported by caregivers that in turn explain the physiological risk (Lin et al., 2012; Torti Jr et al., 2004). The prevailing view in the literature is that caregiving poses a detrimental risk on people's physical health via prolonged exposure to stress and by enabling unhealthy behaviors (Schulz & Sherwood, 2008; Vitaliano et al., 2003). Independent of the uncertainty of the degree or type of physical outcome, caregiving can compromise an individual's physical wellbeing. Fortunately, many caregivers develop coping aptitudes that help mediate the negative psychological effects of caregiving, such as depression or apathy resulting from the illness (Schulz & Sherwood, 2008). However, in occasions when the stress exceeds the coping capability of the individual, then psychological and physical distress result.

Who Provides Family Caregiving

In the United States, according to the National Alliance for Caregiving (NAC) and the AARP Public Policy Institute 2015 caregiving report, women carry out 59 percent of family caregiving . Caregiving for the elderly, the sick, and the young has historically been defined as women's work. Consequently, the observed gender differences in caregiving are rooted in this patriarchal historical view of gendered tasks (Graham, 1983, 1993). These normative gender values of caring have been internalized, are not questioned, and can be punitive to women who deviate from them (Aronson, 1992). This is grounded in the belief that women are better nurturers, that they are innately different than men, and that they possess traits that favor their role as caregivers (Abel & Nelson, 1990). Currently, women are still expected to carry out most of the family caregiving despite significant changes in gender roles where women are also major contributors to the workforce.

Gender influences how caregiving is performed. Although men are also family

caregivers, there are differences in the type of caregiving tasks they perform (Hong et al., 2014; Miller et al., 1992). Women take a more immersed, hands-on approach compared to men, who are more emotionally detached and may assist with instrumental types of issues such as managing finances and legal affairs (Abel, 1991; Hong & Coogle, 2014). Generally, female caregivers are more emotionally connected to the care-recipient. Female caregivers overall report more negative experiences and greater burdens (Gibbons et al., 2014; Lin et al., 2012; Miller & Cafasso, 1992). Additionally, female caregivers rely less on community structures for support (Abel & Nelson, 1990; Sun et al., 2008).

In sum, general family caregiving is complex and intertwined with multiple social-political, economic, and interpersonal factors. As explored in this study, this complexity is compounded further by disease specific factors such as those found in dementia.

Typical Dementia Family Caregiving

The complexity of caregiving is even greater for chronic, debilitating illnesses that elicit greater caregiving resources, such as dementia disorders. Although all caregiving presents challenging situations, not all caregiving is the same. Who you care for defines the caregiving situation; as such, caring for an individual with dementia has its own and distinct challenges. Below we explore why dementia caregiving is particularly concerning and how the dementia symptomology elicits a specific set of demands, stressors, and needs.

Impact of Typical Dementia

Caregiving in dementia is increasingly becoming an important public health concern as the incidence of dementia increases. Alzheimer's disease, the most common dementia, is a growing national problem. In 2017 an estimated 5.5 million Americans lived with a diagnosis of Alzheimer's disease. It is projected that with the growth of the older population, the number will

increase 3-fold by the year 2050 when an estimated 13.8 million people 65 years or older are expected to be diagnosed with Alzheimer's disease (Alzheimer's Association, 2017). The growth in dementia implies greater reliance on families to provide care. According to the AARP, in 2015, one of the top problems or illnesses eliciting caregiving was a dementia or a cognitive problem; 24 percent of all caregivers over 50 years of age reported providing care for an adult with a cognitive-related issue.

Informal dementia caregiving entails distinct emotional, physical, and social-economic challenges to families. The dementia caregiving literature addresses an extensive number of stressors the caregiver may face due to the particularities of the dementia (Haley et al., 1987; Vitaliano et al., 1991). Dementia can be a progressive and debilitating disease where those afflicted lose their ability to function independently (Mendez et al., 2003). The illness may affect memory, mood, and language, as well as alter the patient's behavior and personality, resulting in a decreased ability to self-care. As a result, care-recipients rely more on family and friends for caregiving aid. Hence, dementia caregivers have to deal with a continuously deteriorating illness that involves constant vigilance, arduous physical tasks, and a distressing emotional burden (Haley et al., 1987). Currently there is no cure or known clinical treatments to effectively stop or slow the progression of any of the dementia subtypes (Alzheimer's Association, 2018).

Consequences of Dementia Caregiving

Burden and Distress

The intensity of care involved in dementia caregiving is a growing concern. Providing care for someone with dementia was reported to be more burdensome and stressful than caring for a person with a purely physical disorder (Ory et al., 1999). Dementia caregivers reported experiencing higher physical and emotional strain than non-dementia caregivers (Pinquart &

Sörensen, 2003). This may be due to the lengthy duration of illness and inevitable cognitive and physical decline of the care-recipient, which results in prolonged exposure to stress. Also, dementia caregivers often face a wide-range of psychologically strenuous tasks, such as persistent vigilance of the care-recipient due to wandering risk and management of disturbing behaviors due to changes in personality (Mendez & Cummings, 2003). There may be a progressive aspect of this illness that continuously brings about new challenges. The caregiver is faced with an increasing and fluctuating exposure to stress that often starts before the diagnosis of the disease and continues well beyond the death of the patient (Aneshensel et al., 2004; Aneshensel et al., 1995). The trajectory is long, usually lasting between 3-15 years (Vitaliano et al., 2003). The caregiver is often ill-prepared for the role and, consequently, lacks the coping abilities to handle its demands (Aneshensel et al., 1995). Dementia caregivers readjust to the new challenges—coping with the grief of what has been lost while anticipating future losses.

Grief

Feelings of grief contribute greatly to caregiver outcomes in dementia. Grief refers to feelings of sorrow due to loss. The typical grief, known as bereavement, is grief and sorrow that occurs after a person dies (Jones et al., 1992). However, it is now recognized that feelings of loss may arise prior to death, particularly for chronic, terminal illnesses. Hence, there has been movement to consider pre-death, or anticipatory grief, which occurs prior to death of the family member. Furthermore, there has been increased research in caregiver grief, particularly as experienced by dementia family caregivers (Collins et al., 1993; Jones & Martinson, 1992) (Arruda et al., 2016; Chan et al., 2013; Large et al., 2015; Lindauer et al., 2014).

The literature has identified a complex array of factors that contribute to dementia caregiver grief due to loss of person and relationship, loss of hope, expectancy of death, post-

death relief, and caregiving reflections, the latter occurring post-death (Collins et al., 1993). Pre-death has been defined, within a caregiving context, as the caregiver's response to the care-recipient's dementia changes that result in detrimental caregiving emotions (Collins et al., 1993; Jones & Martinson, 1992). Furthermore, pre-death grief is defined by caregiving situation-specific factors (Lindauer & Harvath, 2014).

In sum, typically the dementia literature assumes sameness among dementia caregivers and fails to account for the heterogeneity within dementia caregiving. Who you are, whom you care for, and the subtype of dementia profoundly delineates the caregiver condition. Hence, it is necessary to identify these dementia particularities to understand the distinctive challenges faced by these caregivers.

In this study, I focus on family caregiving of a rarely studied dementia group: those caring for a spouse with EOD occurring before age 65. Since dementia caregivers are typically caring for older adults, this "premature" illness situation also results in "premature" spousal caregiving or "off-time caregivers." Examining the prominent issues involved in EOD off-time caregiving will highlight these caregivers' specific needs and challenges with an objective of informing future interventions.

What is Off-time Caregiving for Early-Onset Dementia (EOD)?

The recognition of dementia, once assumed primarily as a disorder of the elderly, is increasing in younger individuals and presents unique challenges to both individual families and society. EODs afflict individuals before the age of 65 years with a mean age of onset between 40 and 50 years of age (Hodges, 2001). The EOD category is based on an arbitrary cut-off age of 65 years (Mendez & Cummings, 2003). Although younger off-time caregivers share many of the same issues as those seen by late-onset dementia caregivers, there are additional unique features

that shape the EOD caregiving experience. However, the issues and needs of this group have yet to be sufficiently addressed in the literature.

Although the prevalence of this type of caregiving is uncertain, the few available studies indicate that EOD caregiving poses severe negative consequences on caregivers, such as distress due to the timing of the caregiving (van Vliet et al., 2010). Furthermore, there are features associated with the early-onset condition that may be responsible for the increased risk for detrimental psychological and physical outcomes observed in EOD caregiving (Kaiser et al., 2006).

Impact of EOD

EODs are rare illnesses that are relatively unexplored and possibly under reported. According to the Alzheimer's Association, an estimated 200,000 people nationally have an EOD condition, or 4 percent of the dementia population. However, other studies indicate a higher prevalence of EOD (Fujihara et al., 2004; McMurtray et al., 2006). A study among U.S. veterans found that 30 percent of those diagnosed with a dementia had an onset before the age of 65 (McMurtray et al., 2006). Although the prevalence of EOD is much lower than that of LOD, the prevalence is still significant; estimates suggest 38 to 260 per 100,000 dementia cases have an onset of between the ages of 30 and 64 (Lambert et al., 2014). Furthermore, the risk of EOD increases with age. For individuals ages 55-64 the prevalence can be as high as 420 per 100,000 (Lambert et al., 2014). Also, the rates are suspected to be even higher because EODs are often misdiagnosed (Alzheimer's Association, 2006). Obtaining an EOD diagnosis is in itself a difficult process, often requiring many years of visits to multiple health professionals (Luscombe et al., 1998). The diagnosis of EOD is based on specific clinical criteria for each dementia subtype—illnesses that individually are very uncommon and often misdiagnosed by providers.

Consequences of EOD Caregiving

Although the prevalence of EOD is lower when compared to LOD, the impact of the illness on early-onset caregivers appears to be greater. EOD caregivers have greater burden, distress, and depression than LOD caregivers (van Vliet et al., 2010). There are multiple factors that explain the greater burden reported by these caregivers. Firstly, from the patient outlook, these uncommon dementias often manifest different symptomology (Werner et al., 2009). Secondly, for EOD caregivers, this illness elicits an array of demands and stressors with fewer resources to help them manage (Spreadbury et al., 2017). Also, EOD caregivers may confront secondary stressors that arise due to caregiving at an “off time,” which keeps them from fulfilling their expected life-course stage.

Compared to their LOD counterparts, EODs have greater dementia heterogeneity, more varied symptoms, a different progression, and a higher genetic link (Mendez, 2006; Mendez et al., 2012). EODs have a spectrum of dementia profiles that include Alzheimer’s disease, frontotemporal lobar degeneration, vascular dementia, and Lewy-body dementia, whereas LOD primarily presents as Alzheimer’s disease (Mendez, 2006; Werner et al., 2009). While the typical LOD is characterized mainly by memory difficulty, in EOD there may also be impairments in language, visual-spatial, and executive functions (Mendez, 2006). Additionally, EOD patients may present with greater neuropsychiatric impairment such as changes in behavior and personality (Mendez, 2006). Behavioral variant frontotemporal dementia (bvFTD), the second most common EOD, is characterized by personality changes, decreased insight and self-regulation, hyper-orality, and repetitive acts (Rascovsky et al., 2011). Additional behaviors seen in EODs include apathy, poor judgment, depression, disinhibition, psychosis, and anxiety (Mendez, 2006). EOD patients exhibit a diversely impaired psychiatric profile (Mendez, 2006;

Mendez & Cummings, 2003). The psychiatric impairment may alter social relationships, particularly with family members. This occurs at the prime of the care-recipients' lives when they are still child rearing, working, and building their lives (Luscombe et al., 1998).

Lastly, EOD patients lack access to appropriate long-term care services because they are too young to qualify for these subsidies (Alzheimer's Association, 2006). Additionally, if they are able to pay, the services are often inadequate to meet their needs (Alzheimer's Association, 2006). Furthermore, younger dementia patients often use formal caregiving less often than their older counterparts (LaPlante et al., 2002). In sum, these patients have a much more severe and an atypical form of dementia for which there are only a few appropriate services available.

The care-recipients' impairments may cause an abrupt and unexpected disruption in the lives of the primary caregivers and their families. The caregivers may be ill-prepared to take on the caregiving role and often encounter considerable difficulties managing the caregiving situation. These "off-time" caregivers are prematurely thrust into this new situation, which diverts them from their expected life-course. Their situation is different from that of LOD caregivers for whom caring for an older person with dementia is a normative family obligation or experience. LOD caregivers are mindful and somewhat prepared for the possibility of cognitive impairment occurring among their elderly relatives. Furthermore, LOD caregiving is becoming more common with the increasing baby-boom population, which will decrease access to affordable, formal caregiving services due to higher demand (Alzheimer's Association, 2018).

Who are EOD Caregivers?

In EOD it is primarily the spouse, or on a few occasions the parent, who will take on most of the caregiver responsibilities (Lima et al., 2008). For EOD spouses, caregiving is added to their other obligations such as child-rearing, work, and constructing a marital stability. For

older parent-caregivers, caring for a child with dementia is also atypical, and it compounds their already challenging lives. Often they are caring for an older spouse and may be dealing with their own age-related ailments.

EOD caregiver concerns are often related to being out of sync with their existing life-course stage (van Vliet et al., 2010). In EOD, younger caregivers expressed greater emotional concerns from the illness (Luscombe et al., 1998). Those in the labor market who are also child-rearing report greater overall difficulty (Cabote et al., 2015; Ducharme et al., 2013). A review by Vliet et al. (2010) found that, in qualitative studies, the predominant themes causing distress for EOD caregivers were financial concerns, workforce participation, employment, marital relationships, and loneliness. An EOD caregiver is described in this study literature a “harassed person, beset by psychological problems, financial worries, loss of employment, and family conflict” (p. 329) (Luscombe et al., 1998).

An off-time spousal caregiver is typically dealing with younger children who themselves may be experiencing psychological and emotional problems due to their parent’s dementia. A study found three-quarters of caregivers surveyed reported their children experienced emotional and psychological issues (Luscombe et al., 1998). These children were more likely to have problems at home and at school (Luscombe et al., 1998). Parenting poses a greater challenge when parental issues extend beyond common childhood and teenage issues; they may be dealing with children who are also caregiving and are facing their parent’s progressive disease and mortality (Shifren, 2009). The caregiving experience has long-term consequences for the children as well as the primary caregiver (Shifren, 2009).

In EOD, most caregivers report financial concerns (Luscombe et al., 1998). The diagnosis brings the loss of the patient’s income and potentially that of the caregiver. Care-recipients may

lose the ability to perform their work and may either lose or quit their jobs prior to attaining a diagnosis, resulting in the inability to collect disability benefits or qualify for government aid (Alzheimer's Association, 2006). With loss of employment, most lose their employer-based medical insurance and incur substantial medical debt or pay high premiums for individual insurance (Alzheimer's Association, 2006). The EOD caregivers are in their prime earning years, and this unexpected caregiving situation negatively influences their career and earning potential. Most caregivers working at the time of diagnosis report either an inability to work or a reduction to part-time work due to caregiving demands (Luscombe et al., 1998). The consequences are deeper than lost wages. Caregivers potentially lose career fulfillment, promotional opportunities, pensions, and overall financial stability (Harris et al., 2004; Sperlinger et al., 1994). Mounting medical and financial concerns contribute to the caregiver's feeling of stress and burden.

Additionally, EOD caregivers lack resources to help them manage their needs. These middle-aged caregivers often fall through the net due to a caregiver resource network biased towards the elderly (LoGiudice et al., 2005). Across studies, there is consistent dislike by caregivers of the formal support systems available to them (Luscombe et al., 1998; van Vliet et al., 2010). There is stigma associated with EOD where most service providers lack understanding of the illness and often fail to accommodate both patients and caregivers (Lockeridge et al., 2013). Additionally, caregivers are dealing with their own feelings as they confront this prejudice in care, which may encourage them to opt out from accessing services and become increasingly more isolated (Lockeridge & Simpson, 2013).

Caregiving tasks performed by off-time dementia caregivers can also be very different compared to LOD-related tasks. For example, EOD caregivers express greater burden because they need to manage behavioral problems in the care-recipient (Arai et al., 2007). Overall, EOD

caregivers express greater difficulty (Arai et al., 2007) and burden (Freyne et al., 1999) than LOD caregivers. A 2010 review looking at the impact of EOD caregiving on caregivers could not conclude differences in level of burden, stress, and depression between EOD and LOAD caregivers (van Vliet et al., 2010). However, EOD caregivers consistently had high levels of stress that resulted in mild to severe depression (van Vliet et al., 2010). However, most of this information is based on a limited number of studies with stated limitations.

The literature on EOD dementia caregiving grief is minimal—only a handful of studies address grief in EOD caregiving (Ducharme et al., 2013; Spreadbury & Kipps, 2017). These studies indicate that, for EOD caregivers, grief is due to the loss of the care-recipient's personhood, the relationship they shared, the caregiver's own and future plans and aspirations, and a loss of the normal life they knew (Ducharme et al., 2013; Spreadbury & Kipps, 2017). Hence, not much is known about the experience of those who provide dementia caregiving at an unusually early age.

Methodological Challenges in EOD Literature

Methodologically, the EOD literature adopts the typical approach seen in normative caregiving where there is a bias towards stress paradigms, which focus on the negative outcomes of caregiving. Consistently, the literature focuses on the detrimental psychological or physical effects of caregiving and reports less on positive caregiving experiences. Moreover, these studies have methodological challenges that compromise generalizability. Sampling issues are of major concern because of small sample sizes. In the only two reviews looking at EOD, samples ranged between 30 to 100 caregivers (Millenaar et al., 2016; van Vliet et al., 2010). Additionally, the studies used convenience samples where the caregivers were primarily recruited from organizations providing dementia-related services. Hence, the samples may represent a

population already receiving services, has access to health insurance, and has a higher level of education and socio-economic status.

Thirdly, most of the studies use a cross-sectional design and lack non-caregiver or non-EOD comparison groups. The design is a limitation, especially when studying chronic exposure to stress, because stress responses are susceptible to external events and situations (Luecken et al., 2004). A single event evaluation is likely to be influenced by other non-caregiving-related stress-eliciting confounding variables, such as existing caregiver medical conditions.

Lastly, measurement issues are noticeable in the literature. There is a lack of standardization of principal caregiver variables across caregiver studies. For example, there is inconsistent operationalization of the subject variables “caregiving” and “caregiver” across studies. Currently, the literature lacks a standard definition or criteria defining who is a caregiver (Giovannetti et al., 2009). For those who did provide a definition it was often a broad one such as “in-home care to spouses with a documented diagnosis of AD.” Walker (1995) defined caregiving as “the act of providing assistance to family members beyond routine life interactions.” According to O’Connor (2007) the caregiver is commonly established by self-definition and is often operationalized with varied definitions. Self-definition is complex and influenced by personal values and beliefs of norm behavior in a relationship (i.e., often there are duties described by ADL scale often performed as part of the spousal role). The absence of a general definition of caregiving has serious implications for those working to understand the composition and number of caregivers (Giovannetti et al., 2009.).

Furthermore, defining when caregiving begins is not straightforward because the tasks associated with caregiving are masked by typical relationship dynamics. For example, there is the “genderization” of care, and unwillingness of people to label it caregiving (O’Connor, 1999).

Within a relationship, there are implicit expectations, often dictated by social norms, regarding gender task distribution (Abel, 1991). This is especially true with female spousal caregivers who, prior to the illness, routinely performed many of the tasks labelled caregiving. This becomes problematic because existing surveys do not routinely ask if performing the task is a change after onset of illness (Giovannetti et al., 2009).

Lastly, the dependent variable in the caregiver literature is typically a measure of caregiver burden or psychological distress. These variables are self-reported measurements that ask caregivers to rate their mood or burden. Although the instruments have been extensively used with dementia caregivers and are known to be reliable measures of distress and burden, concerns regarding their internal validity persist. There may be other contextual factors, not directly related with the caregiving role, which influence mood and burden ratings. Secondly, cultural-specific factors that influence the understanding of questions and responses are often not addressed in the literature. Additionally, the study design assumes that all participants will understand the questions and answers in the same way.

Overall, even within this scarce and imperfect literature, there is an indication that providing care for adults with EOD involves an array of distinct factors, burdens, and challenges. Hence, the purpose of this study is to better understand the experiences of EOD caregivers with the aim to bring awareness of the distinctiveness of this dementia caregiving—specially to bring to the forefront that not all dementia caregivers are the same. The case of EOD individuals and their families provides an opportunity to deconstruct salient aspects of the caregiving experience.

Parent Study and Preliminary Findings

This caregiver study expands on an existing parent study, described below. For the present caregiver study, we collected, concurrently, additional caregiver focused data from the caregivers

of patients enrolled in the parent study. We linked the caregiver data with care-recipient measures to assess the influence of the disease on the caregivers. Thus, this caregiver study benefits from extensive information on the care-recipient, the primary caregiving stressor. Below, is a brief description of the parent study and its preliminary findings. The following chapter, Chapter 2, “Methodology,” describes relevant design aspects from the parent study that involved the current caregiver study.

Parent Study

This caregiver study was conducted as part of a parent study performed between 2009-2015. The parent study is a National Institutes of Health-funded study (RO1AG034499, Dr. Mario Mendez, Principal Investigator) conducted at the University of California, Los Angeles, and the VA Greater Los Angeles Healthcare System entitled, “Multidisciplinary Study of Social Behavior and Emotion in Frontotemporal Dementia.” This project examined patient-caregiver dyads (care-recipient and caregiver) diagnosed with bvFTD and EOAD as well as matched normal participants. The aim of the parent study was to define changes in social behavior in those afflicted with bvFTD compared to EOAD and normal individuals.

The parent study proposed the following three specific aims: (1) to characterize the alterations in social moral emotion (SME) in patients with bvFTD using ethnographic observations and behavioral measures, (2) to document the loss of SME in patients with bvFTD compared to patients with EOAD and normal controls using objective psycho-physiological measures, and (3) to assess correlations between alterations in SME and regional structural changes on magnetic resonance image (MRI) scans analyzed with cortical mapping techniques. Although the study

was not intended to investigate caregiving, researchers collected caregiver data linked to the parent study to understand the lived experience of EOD caregivers.

The required permissions were obtained through the UCLA Institutional Review Board (IRB). This caregiver supplement study was covered by the same IRB permission of the parent study.

Preliminary Findings

The parent study has yielded much information that can benefit the present study; primarily it has characterized the EOD patients and their impairment. The parent study, described below, revealed group differences in socioemotional behavior, psychophysiology, and brain imaging within an EOD sample. A study by Joshi et al. (2014) using the Scale of Emotional Blunting found bvFTD patients have marked differences in emotional blunting from their pre-morbid status when compared to early-onset Alzheimer's disease (EOAD) participants. Additionally, caregivers were found to be reliable informants of the patients' social impairment where they provided a more accurate assessment of emotional blunting than did clinicians. A second study by Barsuglia et al., (2014) examined the utility of the Scale of Socioemotional Dysfunction (SDS) to discriminate differences in social dysfunction within EOD. It reported that bvFTD participants had significantly greater abnormal social behavior compared to EOAD. Specifically, this paper presented a scale that captured the social- interpersonal profile of the bvFTD patient as described in the clinical diagnostic criteria by looking at socially inappropriate behavior and loss of manners, as well as loss of empathy, with emphasis on decreased social interest, personal warmth, and interpersonal connectedness. In addition, this paper showed that both dementia groups had high scores on the Clinical Dementia Rating (CDR)— scores that would categorize

them as cognitively impaired. The reported, (CDR) scores, mean 1.13 ± 0.47 for the bvFTD and 0.75 ± 0.26 for EOAD, are within the impaired range compared to a normal population.

Both Barsuglia et al., (2014) and Joshie et al (2014) found that bvFTD caregivers reported significantly greater caregiver burden on the Zarit Burden Interview (ZBI) compared to EOAD caregivers. In addition, variances in the patients' neuropsychiatric profiles were reported. Patients with bvFTD had significantly greater presence of apathy, elation, disinhibition, aberrant motor behavior, and eating symptoms while EOAD patients had greater depression. Additionally, Carr et al. (2016) found that bvFTD patients had social agnosia, lacking the ability to appraise theirs and others emotions when compared to EOAD patients. Paholpak1 et al. (2016) found generalized impulsivity disinhibition in both bvFTD and EOAD. The bvFTD patients showed greater disinhibition under circumstances involving interactions with others.

The patients in this parent study had disturbances in social behavior, particularly those with a bvFTD diagnosis. Those with bvFTD showed disturbances in attribution of intimacy and the ability to denote living status. Both vbFTD and EOAD had disturbances in attribution of agency (the capacity of an actor to act in a given environment) (Sylvia S Fong et al., 2017). They had disturbances in moral behavior where EOD patients had disturbed care-based morality, moral decision-making capacity using emotional empathy, and greater impairment in those with bvFTD compared to EOAD. They both relied more on rule-based morality, or the automatic application of social conventions. These patients, particularly those with bvFTD, may have impaired moral reasoning leading to decisions divorced of emotion. Moral decisions biased toward rational rather than empathy-based (S. S. Fong et al., 2017).

Observational studies of these patients corroborated these findings where those with bvFTD displayed impaired social behavior in ethnographic studies. Mendez et al. (2013) coded a

one-hour mealtime video of patients and caregivers for impaired verbal and non-verbal deficits and found bvFTD participants had significantly greater impairment than the EOAD patients or control caregivers. The bvFTD patients were distinguishable by their notable decrease in tact and manners and lack of “you” comments, indicating they failed to take the other person into account. Barsuglia et al. (2014), in a qualitative analysis of ethnographic observation, described three salient social-behavioral categories describing bvFTD participants. The bvFTD patients displayed diminished “interpersonal relationship interest and initiation.” They failed to engage with others, ignored direct questions, and did not initiate conversation. In addition, they “lack social synchrony” in social interactions. In conversation they provided abnormal and brief/impooverished responses, did not ask questions about self or others, and failed to use empathetic responses. Lastly, they had “poor awareness and adherence to social boundaries and norms.” They were unaware of correct personal distance, used inappropriate language, and humor and over self-disclosed.

Objective measures of impairment were also reported in the parent study. . On psychophysiological testing, bvFTD patients show lower reactivity, measured by skin conductance, compared to the EOAD and normal control sample when exposed to a startle response (Joshi et al., 2014). Additionally, emotional blunting ratings were negatively correlated with skin conductance indicating the bvFTD patient’s increased apathy may lead to alterations in their psychophysiology. The EOAD sample had greater heart rate deceleration as an orienting response compared to a normal control sample, which correlated with greater anxiety (Joshi et al., 2017). There was decreased heart rate deceleration as an orientating response to social stimuli for bvFTD compared to normal controls, correlating with increased emotional blunting in bvFTD. Imaging studies established a diseased brain with changes in varied brain regions

depending on the type of EOD diagnosis. Lu et al. (2013) used diffusion tensor imaging (DTI) to look at white matter integrity between bvFTD, EOAD, and normal matched controls; the study found that bvFTD patients had significantly more white matter breakdown. There was also a positive correlation between emotional blunting and white matter breakdown. Lee et al. (2014) used tensor-based morphometry (TBM) to examine gray matter in bvFTD and described neuroanatomical correlates to symptoms of emotional blunting. The study found that bvFTD patients had smaller brain volume bilaterally in their frontal lobes, while EOD patients had smaller brain volume bilaterally in their temporal lobes and their left parietal region. The emotional blunting correlated with right anterior temporal volume, indicating right-sided atrophy involvement in symptoms of emotional blunting. In sum, these EOD patients are highly impaired and display heterogeneous symptomatology related to the type of dementia.

Theoretical Considerations

In response to an increased reliance on family caregiving, caregiver research has proliferated and is being studied in multiple disciplines. However, most of the research is not theory-driven; concepts and issues are examined without testing a caregiver model or theory (Berg-Weger et al., 2003). The few with a theoretical framework focus primarily on the effects of caregiving-related stress and burden on a caregiver's mental and physical health status (Knight & Sayegh, 2010). Other studies employ a variety of theoretical constructs ranging from feminist theory to the biomedical model. Hence, caregiving has been conceptualized across varied disciplines and in an array of spheres, from the personal behavior, inter-group or family interactions, to social political and economic structures. These have enriched as well as captured the complexity of caregiving, an issue requiring a wide-ranging approach able to represent its multi-dimensionality. However, to date, a comprehensive model or theory has yet to be developed and tested.

In this project, I use two prominent conceptual approaches to provide theoretical insight into the multi-dimensionality of EOD caregiving. The approaches include (1) the caregiving stress process model, which is an individual-level theory examining caregiver-related stressors; and (2) the life-course theory, a micro and macro theory focusing on a person's temporality and context. Factors in both models contribute to the understanding of the burden and distress experienced by EOD caregivers. These models were integrated to conceptualize a caregiver-interconnected model that can simultaneously account for these different layers and may help define the overall EOD caregiver experience.

Caregiving Stress Process Model

The caregiving stress process model, the predominant approach in caregiving research, looks at how caregiver-specific stress and coping strategies affect individuals (Pearlin et al., 2013; Pearlin et al., 1981; Pearlin et al., 1990). This stress approach is based on the assumption that caregiving is burdensome and can result in unmanageable stress that may compromise a caregiver's health (Zarit et al., 1989). While there is a significant amount of literature that supports this approach, the caregiver literature has been disproportionately tilted towards the negative effects of caregiving, often overlooking that some caregivers are not stressed by the role and many report positive effects of caregiving (Aneshensel et al., 1995).

In the 1980's, despite the growth of caregiver research and the existence of separate stress and coping models, most research was disjointed, failing to consistently move knowledge forward. Thus, researchers concerned with the theoretical deficiencies of the field worked toward creating models that addressed the need for focused, measurable, and sophisticated caregiver research. With this aim, Pearlin and colleagues (1990) put forth the caregiver stress process model, which has become the backbone of caregiver research. The caregiver stress process model is still

the main theoretical framework employed in the literature to assess caregiving issues in most illnesses, including dementia (Pearlin & Bierman, 2013). The model consists of the following four domains: (1) stressors (factors or “conditions” that lead to personal stress), (2) outcomes (consequences of stressors), (3) moderators (factors that modify or regulate the stress-outcome interaction) and (4) contextual factors (social, cultural, economic, and political factors that may have additional effects on the caregiver).

Stressors are external occurrences and experiences faced by caregivers that often result in damaging health outcomes (Pearlin & Bierman, 2013). These external stressors may result in distress due to a caregiver’s inability to fully counteract or adjust to the stressor. The stress process model provides a comprehensive configuration of the precursors of caregiver stress. This model introduced the concept of “stress proliferation,” which is based on the concept that people’s stressors do not manifest in isolation but interact with existing stressors (Pearlin et al., 1990). The caregiver stressors are subdivided into primary and secondary stressors (Pearlin et al., 1990). The primary caregiver stressor refers to the original stressor influencing the caregiver at the onset of family caregiving; this includes the care-recipient’s impairment or disability and the caregiver’s own stressors (i.e., other existing employment or family stressors). The secondary stressors are those that proliferate from primary stressors and can either be a direct consequence of caregiving or due to changes in the caregiver’s perception of the situation (i.e., intra-psychic). The role stressor, a primary stressor, refers to a conflict and/or issue that may arise due to the demands of caregiving, such as family conflict, economic problems, or declining social life. The intra-psychic stressors refer to changes in self-perception, which include self-esteem, mastery, feeling captive in the caregiver role, feeling competent in being able to provide care and in the ability to obtain personal gain or enrichment (Pearlin et al., 1990).

A principal mechanism behind stress proliferation is multiple role confusion. As caregivers engage in multiple roles, each role brings about its own set of rewards and stressors, but these roles occur simultaneously with caregiving, which means that caregivers encounter competing demands that may lead to strain. Thus, new stressors proliferate due to tensions between conflicting roles or role sets (Pearlin et al., 1997). Therefore, the manner in which caregivers experience caregiving-related stress is contingent on an array of issues in the caregivers' lives. This may explain divergent reactions to the same caregiving stressor across caregivers.

In conjunction with stress, the impact of the caregiving burden is influenced by intervening factors that may serve as mediators of caregiver stressors and alter the expected negative outcome. Caregivers are not passive recipients of stress and may have personal resources that help counteract the negative effects associated with caregiving stress. There is abundant research looking at personal resources that may mitigate the effects of caregiver stressors (Cohen et al., 2002; Lin et al., 2012). These personal resources are defined as factors that have the capacity to influence the effects stressors may have on an individual's wellbeing (Pearlin & Bierman, 2013). The predominant stress-mediating concepts in the caregiver literature include coping style, social support, and mastery (Folkman et al., 1988; Lazarus, 1974; Pearlin & Bierman, 2013). These resources may also function as stress moderating factors to explain why the same stressor may have different effects across individuals, where not all caregivers report damaging consequences. Coping, as defined by Folkman and Lazarus (1988), is a mediating process of the individual's cognitive assessment of the situational demands, of the nature of the problem, and of the perceived mastery of the caregiving situation (Folkman & Lazarus, 1988). Coping is "the cognitive and behavioral efforts made to master, tolerate, or reduce external and internal demands and conflicts among them" (p. 223)(Folkman et al., 1980). Hence, the "ways of coping model" looks at

various types of coping and the effect these will have on overall stress (Folkman & Lazarus, 1988). The model is based on the notion that how much control people have over the caregiver situation will determine the type of coping they choose. Accordingly, there has been much interest in analyzing coping mechanisms of caregivers to reduce the negative consequences of caregiving.

Additionally, personal control or mastery is seen as a coping resource for caregiver stress. In the stress process model, personal control aligns with mastery, a global construct of control, which is defined as a belief that one is able to control the overall circumstances that are affecting one's life. Although this concept is similar to self-efficacy, it differs in that it takes a global approach and looks beyond personal control or competency pertaining to a specific task. This concept implies that caregivers, to some extent, may be able to control how much they are affected by the challenges of their role.

One of the factors that may mitigate caregiver stressors is social support. The literature identifies three types of social support in caregiving: emotional, informational, and instrumental. These three types of support target major domains affected in caregiving. Lastly, caregiver outcomes include psychological (depression, distress) and physical disability. They are considered indicators of how the primary and secondary stressors affect one's ability to manage while caregiving.

Overall, the caregiving stress process model is a comprehensive standard that has been tested for over 20 years. It has been used in many large-scale caregiver studies such as the REACH study, an NIH-funded intervention program that investigates the effectiveness of innovative interventions to support family caregivers (Coon et al., 2004). The model has also been adapted to examine the effects of caregiving in diverse populations (Aranda et al., 1997).

The caregiving stress process model is well conceptualized with sound measurement capabilities and allows for comparison across different caregiver categories. The theoretical framework accounts for detailed individual factors that generate caregiver stress. It has produced valuable data that has resulted in effective stress-relieving interventions. The purpose of the stress model is primarily to understand caregiving at the individual level and not to account for macro-level factors contributing to a dementia caregiver's wellbeing. For example, in EOD, the caregivers are in a very different stage of their lives than the typical dementia caregivers, which requires consideration of a theory that helps understand the "off-time" component of their caregiving.

Life-course Theory

"The developmental impact of a succession of life transitions or events is contingent on when they occur in a person's life." - Principle of timing in life-course theory (p 12) (Elder et al., 2003)

The main purpose and interest of life-course framework is to see the individual experience within a time-varying contextual perspective (Elder et al., 2003). This construct allows us to study caregiving while taking into account social pathways, developmental trajectories, and social changes (Evans et al., 2008). In addition, it allows the individual caregiving experience to be considered within existing structural frameworks such as race, class, and gender. The higher reliance on informal caregiving along with changes in family structure have made it even more important to see the interconnection of public and private issues in caregiving (Pavalko et al., 2011).

There are five theoretical principles governing life-course framework: life-span development, agency, time and place, timing, and linked lives (Elder et al., 2003). Life-span development looks at human development and aging as lifelong processes. It is a way to account for past personal experiences while looking at the individual's present behavior. It may also

identify the relationship between social change and the individual's development. Agency recognizes that individuals build their own life-course by making choices and taking actions that are shaped, but not fully determined, by the context of their history and social circumstances. The principle of time and place recognizes the influence of historical time and place on people's life-course. The concept of timing recognizes that effects from life transitions, events, and behavioral patterns are dependent on people's stage of life. It recognizes that it is not only transitions themselves that affect individuals, but also how prepared they are to handle these transitions. Lastly, linked lives refers to how social-historical influences are experienced within shared relationships, recognizing that lives (i.e., experiences and life events) are lived interdependently (Elder et al., 2003). Individuals are social beings influenced not only by larger social forces, but also by the interpersonal interactions they share with others.

Life-course framework can help us better understand the EOD caregiving experience within a contextual framework by factoring in the caregiver's life history, experiences, life choices, and relations with others. A study that employed a life-course framework to examine caregiving and the well-being of women correlated caregiver stress and (1) the timing when caregiving occurs (based on their age); (2) duration of caregiving, (3) available resources (i.e., education, well-being) and (4) level of social integration (i.e., multiple relationships and involvement in activities) (Moen et al., 1995). These authors reported the effects of caregiving on women's emotional health are moderated by pre-morbid well-being, prior social integration, and other non-family roles. The duration and timing (age at caregiving) had a negative effect on mastery; the older the caregiver and the longer they cared, the lower the personal control they reported to have over their lives (Moen et al., 1995).

In addition to the specific challenges of EOD, a person's life stage and where they are in the

caregiver process will determine how well they handle the caregiving role. This is an important issue in EOD because the premature occurrence of the disease makes people provide dementia care at an off-time or untimely stage of life. The concept here is that there is a culturally-defined timetable when life events should occur and these are marked by age (Elder, 1975; Hagestad, 1988; Settersten & Hagestad, 1996). Accordingly, the normative timetable for people in their 40's and 50's is that they are in the peak of their careers and child-rearing (Settersten & Hagestad, 1996; Settersten & Hägestad, 1996). Hence, here we proposed that EOD caregiving is an unanticipated off-time life transition because it is not within the "normative" expectations for this age group. Consequently, these caregivers may appraise the caregiver situation differently than in typical LOAD because they are deviating from their life-course (Elder, 1975; Rook et al., 1989).

A Model for EOD Caregiving

The following proposed EOD caregiving framework draws from the stress process model and life-course theory with an aim to guide the analysis of the EOD caregiver experience (Figure 1). The model proposes that multiple interconnected trajectories or "streams" yield the observed caregiver outcomes. The streams in this model were chosen based on relevant issues facing EOD caregivers. The purpose of the model is to organize and identify the central factors that characterize the EOD caregiver experience.

The first stream accounts for the "personal status" or the entirety of their persona. The model proposes that as one comes into caregiving one has a "pre-caregiver identity," which predisposes how one will handle the general caregiver tasks and guides the transformation to a "caregiver identity." This "personal status stream" is influenced by the caregiver's life-course that includes factors such as temporality and historical context, cultural factors, beliefs, and context (i.e.,

economic status, education). EOD caregiving is untimely and non-normative in expected life-course stage and can be considered an alteration for this middle-age age group. In contrast, although dementia caregiving is also an alteration at an older age, it does not include the added life-course issues as it is more expected for dementia caregiving to occur at a later life stage. The historical as well as other contextual factors take account of macro level influences that explain caregiving effects. Overall, this stream will look at all life factors, both stressful and positive, which are unique to these mid-life individuals and may explain their caregiving situation.

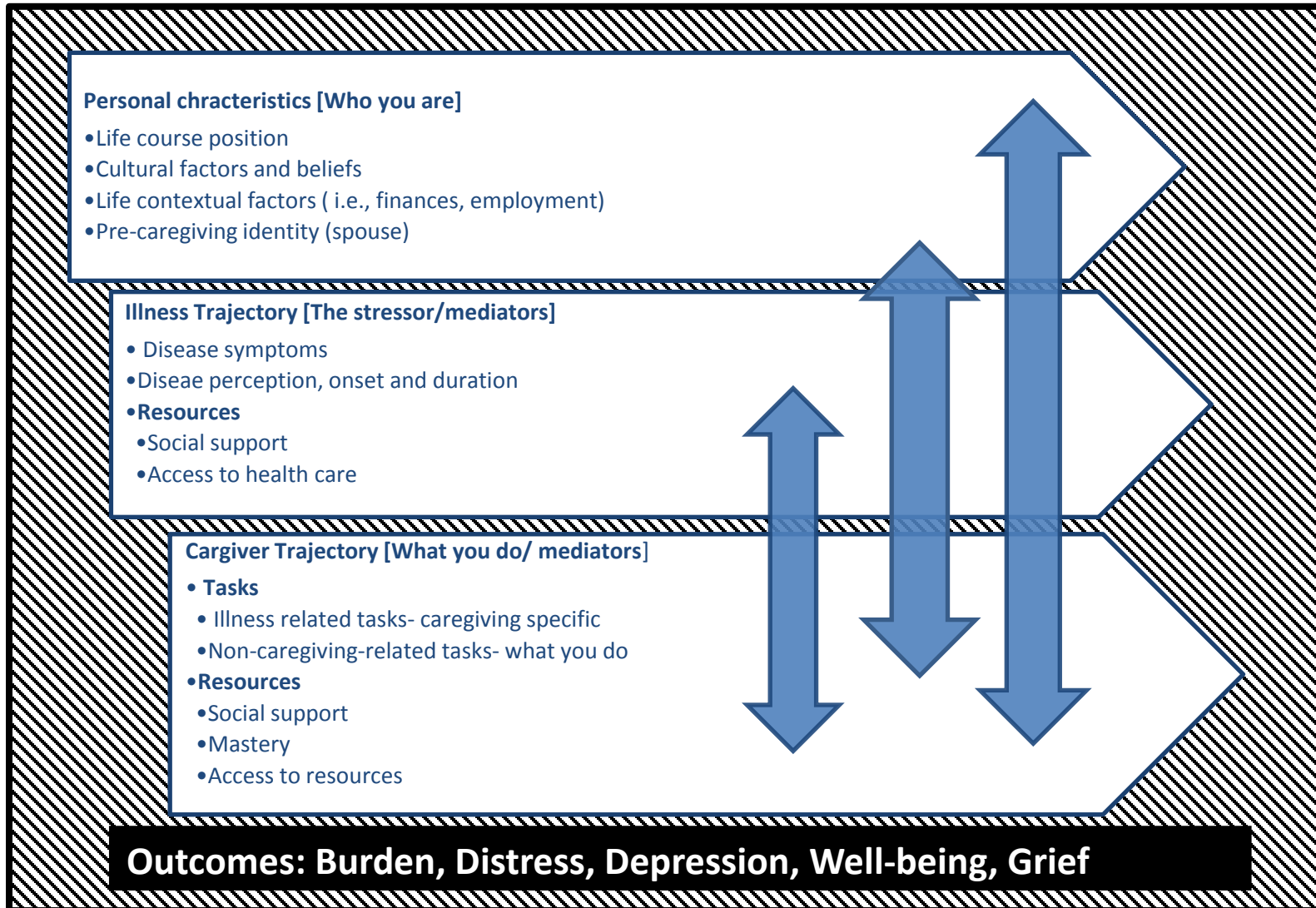
The second stream is the illness trajectory—in this study the EOD trajectory. It entails all issues related to the illness and is the driving factor in the caregiving condition. The onset of the dementia initiates the dementia caregiving situation. Hence, the changes in the illness such as disease subtype, severity, resources, and perceptions will shape the caregiving experience. Since the dementias in this study are chronic and progressive illnesses, the caregiving situation follows a similar and parallel stream or trajectory. The changes in symptoms will determine the caregiving tasks in the caregiving trajectory.

The third stream refers to issues directly associated with the “caregiver trajectory.” This is a dynamic process since these dementias are progressive illnesses with marked changes in severity, symptomatology, and caregiving needs. The stream is composed of caregiver “stressors” and “moderating factors” as proposed in the stress process model (Pearlin et al., 1990). The “primary stressors” will change concurrently with disease progression. EOD, as described above, is different from the more common LOD, and this stream will account for those distinctive features of the disease. Additionally, the “personal status” stream will influence “secondary stressors” as well as “moderating resources.”

The streams are enclosed within a figure that denotes overall outcome, including distress,

depression, or well-being (gray area). It recognizes the caregiver's overall health status and experience as described by the convergence of multiple forces. Additionally, in this model, the outcomes could be positive consequences, unlike many other caregiver models that mainly emphasize the deleterious effects of caregiving. Lastly, these streams intertwine at different stages (represented by arrows) and are continuously re-defined as the caregiving trajectory progresses.

Figure 1: A Theoretical Model for EOD Caregiving



Chapter 2. Methodology

As part of the parent study described above, qualitative caregiver data for the current study was concurrently collected between 2009–2015. This study relied on the parent study for many aspects of its design. Below is a description of the study; however, only relevant aspects of the parent study design are presented.

Approach

This study used a qualitative grounded theory approach—an ideal method to study unexplored issues in EOD caregiving, a relatively rare and understudied dementia population. It endorses an inductive approach to understand unexamined issues such as beliefs, norms, culture, and interconnected psychosocial factors. The aims of this study were to carry out an in-depth textual description of the caregiving process in an EOD population and to gain a thorough understanding of the meaning of this experience from the caregiver perspective. In this study, grounded theory was a useful tool to describe the distinctiveness of the EOD caregiver process. Additionally, it offered a valuable framework to conceptualize issues shaping the lives of EOD caregivers.

Grounded theory is a qualitative methodology with the capacity to dynamically construct a theoretical model that is grounded in, or emerges out of qualitative data (Glaser et al., 1967). However, it is not intended for testing existing theoretical frameworks or for generalizing to broader populations (Charmaz, 2006). Grounded theory emerged from the work of Glaser and Strauss who provided systematic strategies for qualitative research at a time when quantification methods were the most prevalent disciplines (Charmaz, 2006; Glaser & Strauss, 1967). Accordingly, Glaser and Strauss proposed that through systematic qualitative analysis one can construct theoretical explanations for life social processes (Corbin et al., 2008). Grounded theory is shaped

by symbolic interaction theory, which assumes that social reality and the self are created through social interactions and, therefore, depend on language and interpersonal communication (Charon et al., 2009). Specifically, a constructivist grounded theory approach guided this study (Charmaz, 2006). A grounded theory approach follows 6 principles: (1) simultaneous data collection and analysis; (2) analytical codes and categories emerging from the data; (3) constant comparative methods throughout the analysis; (4) continuous theory development throughout the data collection and analysis phase; (5) memo writing to define, elaborate, and interrelate categories, as well as identify gaps; and (6) sampling aimed at theory construction and not generalizability.

Recruitment

The caregiver study utilized the same recruitment strategies, described below, as the parent study. In the parent study, participants and their caregivers were recruited from the UCLA Neurobehavioral Clinic and through direct referrals from other memory clinics within the UCLA health care system. Researchers enrolled 48 EOD care-recipients along with their corresponding caregivers. The study was guided by the following inclusion and exclusion criteria:

Care Recipients:

- Met diagnostic criteria for bvFTD or NINCDS-ADRDA criteria for clinically probable AD.
- Able to understand and complete procedures and to take part in the tests by hearing and understanding instructions and by seeing the stimuli to be responded to.
- English speaking, having acquired English prior to age 13 and using it as primary language.

- Medically stable (defined as absence of medical illness that would interfere with the subject's ability to understand and participate in study procedures).
- Absence of a neurological or psychiatric illness other than bvFTD or clinically probable AD.
- Absence of cortical infarction, other cortical lesion, or significant subcortical lesion on MRI of brain.
- Presence of a caregiver who can facilitate participation in this project. Where there is more than one caregiver, every effort is made to designate the closest relative as the main caregiver.

A caregiver was defined as a family member or friend of the subject who provided assistance to a care-recipient. A study partner had to meet the following criteria to participate:

- Personally visited and interact with the subject at least one time each week for minimally one hour.
- Accompany the subject to each visit.
- Able to provide opinions about the subject's thinking (i.e., memory, language, problem-solving ability), daily activities (i.e., dressing, hygiene, mobility, household chores, and hobbies), and behavior (i.e., mood, sleep patterns, appetite, participation in social interactions).
- Willing to share personal information including feelings of distress about the subject's behavior or feelings of burden by caregiving responsibilities.
- Read, understand, and speak English fluently to ensure comprehension of informed consent form and informant-based assessments of the subject.

- The study enrolled only those caregivers who were determined by the investigator to be capable of compliance with the protocol and whom demonstrated a high probability of study completion.

Study Location

This study took place at the UCLA research clinic for visit one and three, at the Veterans Affairs Healthcare System (VAGLAHS) of Greater Los Angeles psychophysiology lab for visit two, and at the participants' homes for visit four. The visits were scheduled at the convenience of the caregiver. Study procedures were carried out in-person in a private room at the UCLA research clinic or VAGLAHS lab. Only the caregiver and interviewer were present during the interview.

Caregiver Study Sample

Forty-eight dementia dyads completed the parent study. However, for this caregiver study, only caregivers who provided an interview, and who provided care for a spouse with a dementia, were included in the analyses. Thus, since the interviews by non-spousal caregivers did not add information to the process of family caregivers, they were excluded from the analysis to have a homogenous sample of spouses. Initially all 33 spousal caregiver interviews were read and reviewed for content by the author (EJ). Additionally, two were excluded because the care-recipients had a disease onset greater than 65 years. This study reports on 29 caregivers who provided care to a spouse who had an onset of dementia before the age of 65 years.

Parent Study Visits

The parent study consisted of four study visits for data collection; the data for the caregiver study was collected during the first two visits of the parent study. At visit one, care-

recipients and caregivers were screened for eligibility, and they provided informed consent and demographic information. The caregivers completed surveys appraising the care-recipient's behaviors, personality, memory, and function as well as self-reported surveys assessing their own feelings of burden, distress, and depression. The care-recipients underwent a neurological exam and neuropsychological testing, and they completed behavioral and morality surveys.

At visit two, the caregiver provided a one-hour recorded interview focused on their experience with dementia caregiving. At the same time, in a different room, the care-recipients underwent psychophysiology testing and participated in behavioral experiments. The last two visits involved data collection only from the care recipient; during the third visit they underwent neuropsychological testing and a one-hour MRI exam and the in the fourth visit ethnographic observations were performed.

Data collection

Although the parent study collected extensive information as part of the parent grant, only the data pertinent to this study's research question are described below.

Qualitative Data

This study's data source consisted of an intensive semi-structured one-hour interview of caregiver participants. The interviews were carried out by either the author (EJ), a research assistant (MM), or a nurse practitioner (JS)—all members of the study team. All interviews took place in-person during the second half of visit two. The timing was deliberate to allow an opportunity to build trust between the caregiver and interviewer.

The interview guide (see Appendix B) and the concepts underlying it were used mainly as a "point of departure." Appropriate probes were used when applicable. The interview attempted to

obtain the caregiver's lived experience by targeting many domains in the caregiver's life such as caregiver burden, caregiving tasks, interpersonal relationships, and meaning and perception of caregiving and the illness, and caregiving emotional status. Specifically, the interview guide focused on the illness and diagnosis, the caregiver-patient relationship, secondary stressors, social support, and positive aspects of caregiving (see Appendix B).

As the study proceeded, the interviews were guided by emerging concepts and not constricted by the interview guide, while maintaining the interview within the allowable scope of the IRB approved protocol. There were debriefing informal team sessions between study visits and after the interview to note emerging concepts about the patient and caregiver. The research team formulated general impressions of the caregivers throughout the study. Hence, general concepts were identified that helped guide the next interview and informed the coding framework for the analyses. This is consistent with an inductive grounded theory approach where the knowledge gained from prior interviews assists in identifying specific issue of emerging importance. For example, caregiver "anger" emerged as a possible factor in EOD caregivers and this was explored further in subsequent interviews.

There are inherent limitations to the open-ended interviews because participants provided a perspective of their own interpretative reality. Commonly, caregivers were more candid in areas that were more pressing for them in that particular moment—they tended to provide more details and required less probing questions. The interviewees are known to be influenced by the caregiver's lens, which includes their emotional state, the relationship with the interviewer, and self-serving responses and recall distortions (Patton, 1990). It is within this context that these caregivers' responses were evaluated. The caregivers' perceptions were analyzed to understand their

influence on the caregiving experience, life course, and their view of external resources and realities (see data analysis section below). Hence, these inherent limitations support the lack of generalizability of this finding. Albeit, gaining a descriptive preview on the process of caregiving for this rare dementia population was an important dimension of this study.

Quantitative Data

The quantitative data consisted of general demographic information, care-recipient self-reported and informant based measures on illness status, and caregiver self-reported scales of their feelings of burden, distress and depression. At visit one, standard demographic information and the scales were collected for both caregivers and care-recipients. The standard demographic data included age, gender, education, occupation, marital status, and ethnicity. These data provided information on the overall group composition and pointed to potential contextual factors influencing the caregivers.

Care-Recipient Assessment Modules

The care-recipient modules included assessments of disease severity and symptomology. These measures were chosen to characterize the care-recipient's illness, which comprises the primary caregiver stressor in EOD caregiving. The care-recipient focused scales assess the care recipient's level of functional impairment and behavioral disturbance associated with the illness. The scale information was collected from both the caregiver and the care-recipient. The caregivers exclusively provided information about the care-recipients for the following measures: the Functional Activities Questioner (FAQ), which provides an assessment of the care-recipient's functional status; the Neuropsychiatric Inventory (NPI), which provides information on the psychiatric status of the care-recipient; the Scale of Emotional Blunting (SEB), which provides a measurement of the care-recipient's effective and cognitive blunting; and the Socioemotional

Dysfunction Scale (SDS), which provides a measure of social impairment. For the Clinical Dementia Rating Scale (CDR), which is a care-receipt global measure of cognition, the information is collected from both the caregiver and the care-recipient. The Mini–Mental State Examination (MMSE), which is a general measure of cognition, is collected directly from the care-recipient.

The Functional Activities Questioner is a 10-item screening tool used to evaluate activities of daily living independence in patients with dementia (Pfeffer et al., 1982). It appraises an individual's ability to do their own shopping and finances, prepare meals, travel, remember appointments, and follow a discussion or written material. The scales measure level of dependence. Each question is rated from zero (independent) to three (dependent), with a total score range of 0-30 points. A cut-off score of nine or greater or a “dependent” score in more than three activities indicates impaired function and possible cognitive impairment.

The Neuropsychiatric Inventory is an informant-based interview that assesses the presence and severity of 10 neuropsychiatric symptoms/domains over the previous four-week period in dementia patients: delusions, hallucinations, dysphoria/depression, agitation/aggression, anxiety, apathy/indifference, euphoria/elation, irritability/lability, disinhibition, and aberrant motor behaviors (Cummings et al., 1994). The items are scored by multiplying disease frequency and severity. Severity has a rating of 1-3 points and 1-4 points, yielding a possible score in the range of 1-12 points for each question.

The Clinical Dementia Rating Scale is a clinical instrument that evaluates dementia severity (Burke et al., 1988; Morris, 1993). This is a 5-point scale ranging from zero (no impairment) to three (severe). It consists of six domains (memory, orientation, judgment and problem solving,

community affairs, home and hobbies, personal care), which are scored separately yielding a summary and a global score calculated based on a test-specific algorithm.

The Mini–Mental State Examination (MMSE) is a 30-point questionnaire that measures cognition (Folstein et al., 2000). A summary score is calculated by adding all correct answers; any score less than 24 out of 30 points indicates cognitive impairment. Furthermore, scores in the range of 19–23 points indicates mild and those below 19 points indicates severe cognitive impairment (Tombaugh et al., 1992).

The Scale of Emotional Blunting measures lack of “pleasure seeking,” affective blunting, and cognitive blunting (Abrams et al., 1978). This is an objective 16-item scale where patients undergo an interview from which they are assessed using a 3-point scale. The sums of the questions yield a summary score in the range of 0-48 points. A score of 17 points or above indicates a psychiatrically impaired, emotional blunt patient (Abrams & Taylor, 1978).

The Socioemotional Dysfunction Scale is an informant-based 40-item scale that measures social impairment (Barsuglia et al., 2014). Caregivers rate the care-recipient’s social behavior in a 5-point Likert scale (1–5) where 1 = Very Inaccurate, 2 = Somewhat Inaccurate, 3 = Neither Accurate Nor Inaccurate, 4 = Somewhat Accurate, 5 = Very Accurate. The raw data are added to yield a summary score ranging from 40-200 points where the higher the score the greater social impairment.

Caregiver Assessment Modules

The caregiver specific questionnaires are self-reported measures of their own burden, depression, and distress. These measures were collected to obtain an overall profile of caregiver well-being. The measures include the Zarit Burden Inventory (ZBI), which provides a measure of

caregiver burden; the Center for Epidemiological Studies Depression Scale (CES-D), which is a general measure of depression; and the NPI Caregiver Distress Scale, which assesses caregiver distress resulting from the patient's behavioral disturbances.

The ZBI measures subjective burden among caregivers, and it was developed for the dementia caregiver population (Chadarevian et al., 2005; Zarit et al., 1985; Zarit et al., 1980). It examines self-reported burden associated with the care recipient's functional/behavioral impairment and home environment. The questions are scored on a 5-point Likert scale ranging from "never=0" to "nearly always=4." The scores range from 0-88 points where the higher the score the greater the reported burden. Although some of the ZBI score mainly reflects a descriptive score of burden without providing cut-off scores of critical burden levels, studies have shown that a cut-off score in the range of 24–26 points is useful in identifying a burdened caregiver (Schreiner et al., 2006).

The CES-D is a 20-item self-report scale used to measure depression in the general population (Weissman et al., 1977). Total scores range from 0–60 points where a higher score indicates greater symptoms of depression. The CES-D requires participants to rate how often in the past week they have experienced a series of symptoms; scores range from "rarely or none of the time" (less than 1 day) to "most or all of the time" (5-7 days). The cut-off score of 16 or greater is considered a risk for clinical depression for most individuals (Weissman et al., 1977).

The NPI Caregiver Distress Scale component measures caregiver's distresses resulting from reported behavioral changes of the patient (Kaufer et al., 1998). It asks caregivers to rate the level of emotional or psychological distress on a 6-point scale ranging from zero (none) to five (ex-

treme). A total distress score is calculated by a sum of all ratings and yields a possible score between 0-60 points.

This quantitative data in this study was triangulated with the qualitative data. Triangulation compares multiple data sources to allow a concept to be seen or understood more extensively (Guba, 1981; Krefting, 1991). The quantitative data was first reviewed to profile caregivers' contextual factors and then triangulated with qualitative concepts to corroborate inductions. The data were not used to draw conclusions on the sample or to make group comparisons.

Data Management

The quantitative data were entered into data collection forms. Summary scores were calculated for all scales and entered into a Microsoft Access database. The database underwent a systematic data cleaning process to ensure data integrity. The dataset for this study was queried out of the larger dataset and imported into SPSS V.22 for analyses.

The one-hour caregiver interviews were audio recorded, downloaded, and stored in a secure file. They were then transcribed into a text document by staff research assistants. The transcripts were reviewed and stripped of identifiers. The author (EJ) reviewed the manuscripts for transcription quality. Transcripts were uploaded onto Atlas-ti for qualitative analysis (see below for detail description of the analyses.) The Atlas-ti program is a qualitative analytic software tool used to manage data and assist in systematic analyses by extracting and comparing segments of qualitative data. The program helps organize, manage, and code interviews to systematically compare them.

Data Analyses

The data analyses were twofold with a qualitative and quantitative component. The author (EJ) conducted all data analyses using SPSS V.220 and Atlas.ti software.

Qualitative Data Coding

The author (EJ) met regularly with the dissertation chair (SPW) while conducting the qualitative analyses. Meeting discussions focused on all processes of the analyses. Printouts of the code list and selected sample quotes and categories were reviewed and discussed with the dissertation chair (SPW). However, the author (EJ) independently executed the analyses.

Based on existing literature, supported categories were used to initiate the analyses (Kaiser & Panegyres, 2006; Lockeridge & Simpson, 2013; Luscombe et al., 1998; van Vliet et al., 2010). The purpose was to assess if this study, under rigid qualitative analyses, supported or corroborated findings in existing literature. Furthermore, for those concepts that did emerge, a richer description of these categories was explored. This initial exploration was followed by the identification of emerging concepts. The coding was both inductive and quasi-deductive. Although during the coding process new emerging concepts were included, the coding was also guided by the research question and specific aims.

Table 1: Initial Codes from the Literature		
<p>Intrapsychic</p> <ul style="list-style-type: none"> • Burden • Guilt • Loneliness/isolation • Poor emotional well-being • Loss of role • Maintain control • Identify 	<p>Relationship</p> <ul style="list-style-type: none"> • Changing marital relationship • Changing family structure • Family conflict • Intimacy • Parenting 	<p>Work/Finances</p> <ul style="list-style-type: none"> • Meaningful occupation • Employment • Household responsibility
<p>Illness</p> <ul style="list-style-type: none"> • Diagnosis process • Disease stigma 	<p>Coping/Support</p> <ul style="list-style-type: none"> • Social support • Services use 	

The coding process took place between 2015 -2018 and it was systematic and grounded on the data. Coding was contemporaneous in this project—the data were continuously categorized to “select, separate, and sort data” and maintain an analytical assessment (Charmaz, 2006). This was an iterative, dynamic, and multi-step process whereby data was categorized and organized to obtain a substantive theory.

At initial coding, data from the first 10 interviews were coded line-by-line where descriptive labels for lines, story segments, or incidents in the interviews were provided for the entire interview. The interviews were selected based on interview data and diagnosis; the first five interviews were caregivers of bvFTD and EOAD care-recipients. The codes, at this stage, were descriptive or interpretative of the data and included “en vivo” codes obtained directly from the data. Codes from the literature (Table 1), described above, were also included at the initial stage as a way to focus the analyses—however codes were only used and kept if they appear in the data. Although these literature codes compromise a purest “grounded” approach, it was unavoidable as the investigator had performed a literature review prior to the analysis and data collection.

This initial line-by-line coding stage is recommended because it allows researchers to “stick closely to the data.” This grounded approach controls researcher bias by reducing the opportunity to superimpose their own beliefs on the data (Corbin & Strauss, 2008). This initial coding intentionally makes researchers scrutinize data so closely that they distance themselves from their own perspective. They are less guarded and are more open to ascertain explicit processes and uncover salient assumptions while gaining new insights.

The second coding phase was “focused coding.” During this phase the most frequent and significant codes we identified and used to sort the data (Charmaz, 2006). The initial coding stage defined an analytical direction and yielded an extensive selection of codes—over 150 were generated initially. Focused coding entailed a consolidation of codes to a manageable yet meaningful amount. First, similar codes and phrases were grouped. The groups were then assembled to create clusters, which were then labeled into concepts or “super codes” (Eaves, 2001). An additional 10 interviews were then coded with the newly defined concepts. The interviews were coded until saturation was reached, which is defined as the point when new concepts no longer emerge out of the data. The remaining 11 interviews were incorporated and analyzed utilizing theoretical coding. Theoretical coding is the stage of analysis when “super codes”/categories are related to the core category—focus coding substantiate the grounded theory. This occurred during the later stages of the analysis, after axial coding described below.

Simultaneously, during the coding process “constant comparative methods” were employed to compare statements, categories, and incidents within and across interviews (Corbin & Strauss, 2008). This was important as codes were consolidated through Atlas.ti. The least populated or employed codes were collapsed into predominant concepts or dropped from the analyses if they were not supported by other concepts.

Lastly, axial coding was employed to identify the meaning of the data. Axial coding refers to the process of “crosscutting or relating concepts to each other” (Corbin & Strauss, 2008). The properties and dimensions of a category were identified and placed in subcategories. A report was generated for the major categories. This included all quotes related to each category. The reports were reviewed and the dimensions of the category were described in a summary memo.

Memo writing was employed at all stages of the coding process. Memos were used to document and describe any significant issues found in the analytic process. Creating memos assists in "increase[ing] the level of abstraction of your ideas" (Charmaz, 2006). At initial coding, memos were employed to define properties of the codes and categories. During axial coding when the codes were collapsed into categories, memos were again used to explore the embedded or explicit meaning of codes and categories. Hence, memo writing helped analyze the importance of the codes and their interrelatedness.

These memos were essential to formulating the resulting actions of this study. The categories and memos were then sorted for theoretical meaning or theoretical coding. The aim was to analytically sort and identify associations between categories, which then can be compared to make abstract deductions of the data. The continual comparison of categories helped identify relationships within categories and ultimately helped identify the core categories.

Quantitative Analysis

Quantitative statistical analyses were carried out with SPSS V.220. The analyses for the EOD sample consisted of univariate analysis, which describes the distribution of a single variable i.e., central tendency (including the mean, median, and mode), and dispersion (variance and standard deviation).

Trustworthiness

Study trustworthiness in qualitative studies is a method to evaluate research findings and increase study rigor. The goal is to increase the quality of the study while maintaining the significance of the research (Krefting, 1991). Based on the Guba (1981) model of trustworthiness, the following four dimensions are recommended to appraise qualitative findings: truth value/credibility, applicability, consistency, and neutrality. The credibility concept refers to the abil-

ity of the study and researcher to establish credibility of the findings within the context of the study. It answers the question, “has the researcher represented the informant’s realities adequately?” (Guba et al., 1982). In this study, triangulation methods and peer debriefing were carried out to assure the trustworthiness of study results.

Triangulation

In this study, two sources of data were triangulated—care-recipient and caregiver scales and qualitative caregiver interviews—to assure credibility of the findings. The aim of triangulation is to look at the convergence of multiple methods. This helps corroborate that results are not a biased interpretation of the researcher or that a complete and not partial view of the phenomenon is being endorsed (Guba, 1981; Krefting, 1991). The two types of data were compared to verify that the dimensions or perspectives of the emerging concepts in the interviews were consistent with the findings in the quantitative data. Initially, the author conducted an inductive content analysis of the qualitative interviews. These findings were then triangulated with the quantitative data. Hence, as the qualitative data identified emerging patterns or categories, the quantitative data was consulted to corroborate the findings. This form of data triangulation not only strengthens the study design but also increases the trustworthiness and integrity of the results (Patton, 1990).

Peer Debriefing

Multiple peer-debriefing opportunities occurred during the study that helped reveal the investigator’s own biases or pre-conceived assumptions that may compromise results. Key components of trustworthiness were the regular meetings with the dissertation committee chair (SPW), who provided constructive peer debriefing and critique. These meetings identified concerns of neutrality; it safeguarded that the findings were exclusively based on informant and

study-related factors and no other potential biases. These bimonthly meetings between dissertation chair and author (EJ) discussed all logistical study information, addressed methodology issues, reviewed results, and presented opportunities to disclose any thoughts or feelings that may result from interaction with participants (Krefting, 1991).

Additionally, there were regular exchanges with study team members (clinical dementia experts) that helped address some of the trustworthiness issues. The meetings with these experts helped with the transferability concepts of trustworthiness. Transferability and applicability refer to the ability of the findings to fit in another situation where there should be goodness to fit between both contexts (Krefting, 1991). Specifically, there were regular conversations with the Neurobehavior Clinic nurse practitioner (JS) about the categories arising from the analyses and interpretations of the results. She read all interviews, advised on analyses, and reviewed parts of the Results section. Now retired, JS has over 20 years of experience working with dementia patients and their caregivers in research and clinical settings. There were also sessions with the neurologist, (MFM), a committee member who similarly provided his clinical expertise to help inform the analyses and study findings. MFM, the Principal Investigator, has worked extensively with the study data. Additionally, he met with all participating caregivers and care-recipients.

The analytical process is dynamic and data is continuously consulted as the grounded theories were drafted and refined in the following result chapters, Chapters 4-8. Chapter 3 will present summary results from the quantitative scales.

Chapter 3: Who are Early-onset Caregivers and Care Recipients?

This chapter profiles the early-onset dementia (EOD) caregivers and care-recipients in the parent grant’s sample population using quantitative data. It provides information on the degree of burden and distress experienced by EOD caregivers. Additionally, it characterizes the functional, cognitive, and behavioral impairment of care-recipients.

In this caregiver study, we report on 29 EOD caregiver dyads—13 care-recipients diagnosed with behavioral variant Frontotemporal Dementia (bvFTD) and 16 with Early-Onset Alzheimer’s Disease (EOAD). The diagnosis for bvFTD was based on the International Consensus Criteria for bvFTD (Rascovsky et al., 2011). For EOAD, the diagnosis was based on the National Institute of Communicable Disease and Stroke-Alzheimer’s Disease and Related Disorder Association (NINCDS-ADRDA) criteria for clinically probable AD (McKhann et al., 1984). The care-recipient and caregiver measures below were used to provide a general profile of these caregivers and their care-recipient.

Table 2: EOD Caregiver(n=29) and Care-recipient Demographics (n=29)

	Caregiver (Mean(SD))			Care-recipient(SD)		
	EOD (n=29)	bvFTD (n=13)	EOAD (n=16)	EOD (n=29)	bvFTD (n=13)	EOAD (n=16)
Age, Years	57 (12.7)	56.6 (11.5)	57.5(9.4)	58 (7.3)	57.5 (9.8)	58.3 (4.8)
Gender, Female	55.2%	53.8%	56.3%	44.8%	46.2%	43.8%
Education, Years	16 (2.1)	15.3 (2.4)	16.1 (1.8)	16 (2.2)	15.2 (2.1)	16.4 (2.2)
Race (White)	100%,	100%	100%	93.1%	92.3%	93.8%10
Cohabitate	96.6%	92.3%	100%	_____	_____	_____
Years Since Onset	_____	_____	_____	3.3 (1.7)	2.9 (1.1)	3.8 (1.9)

Caregivers and Care-Recipients' Demographic Profile

The caregivers in this EOD sample are primarily late middle-aged, married, and caring for their spouse (Table 2). They have a mean age below 65 years, (57.0 ± 12.7). All the caregivers are family members of the care-recipient. Most often care is provided by the spouse—79.2 percent are spousal caregivers in the parent study. Moreover, primarily women provide the care; 55.2 percent of the sample is female. Ninety seven percent of the caregivers lived with the care-recipient during the study period. The sample is homogeneous by race and ethnicity; most caregivers are white and highly educated with a mean of 16 ± 2.1 years of education.

Many of the care-recipients, similarly to the caregivers, are relatively young—mean 58 years ($SD=7.3$), highly educated, 16 ($SD=2.2$) and predominantly white. They may be early in their disease course with a mean of 3.3 ($SD=1.7$) years since disease onset. The bvFTD and EOAD subgroups in this sample are demographically similar; there are no major differences on age, race, and education.

Care-Recipients' Illness Profile

The care-recipients' are cognitively and functionally impaired with a Mini-Mental State Examination (MMSE) mean score of 23.3($SD= 6.0$) out of 30 and a Functional Activities Questioner (FAQ) mean score of 14.7 ($SD=7.9$) out of 30 where a cut-off score of greater than 9 signifies impairment) (see Table 3). There is indication of psychiatric impairment based on the caregiver's report in the Neuropsychiatric Inventory (NPI) (see Table 4). Accordingly, many of these EOD care-recipients have a high frequency of apathy, disinhibition, and aberrant motor and eating behaviors. However most of this EOD population is not emotionally blunt with a score of 13.4 ($SD= 10.0$) based on the Emotional Blunting Scale. A score of 17 or above indicates a clinically impaired emotional blunt care-recipient (Abrams & Taylor, 1978).

Socially, many of them are impaired. The EOD care-recipients have a mean summary score of 107.3(SD= 42.4) on the social dysfunction scale. Although cut-of scores have not been established for this test, it does provide valuable information on the wide variability of social dysfunction within the EOD dementia subtypes. EOD caregivers, particularly those providing care in bvFTD, may be dealing with individuals that may be considerably socially impaired. However, the wide standard deviation in these care-recipient measures indicates that some caregivers in this sample may be providing care for individuals that may suffer from various severities of impairment in the different domains.

Table 3: Care-recipient and Caregiver Scales			
Domains	Mean (SD)	Mean (SD)	Mean (SD)
	EOD (N=29)	bvFTD (N=13)	EOAD (n=16)
C-Burden (Range= 0-88)	36.9 (19.6)	44.3 (22.7)	31.4(15.4)
C-Depression (Range= 0-60)	14.9 (11.6)	20.4 (13.2)	10.5(8.1)
CR-Cognition (Range 0-30)	23.3 (6.0)	22.9 (7.0)	23.7(.3)
CR- Global cognition (Range 0-2)	0.88 (0.4)	1.1 (0.4)	0.7 (0.3)
CR-Function (Range: 0-30)	14.7 (7.9)	19.2 (7.0)	11.3(7.0)
CR-Emotional blunting (Range: 0-48)	13.4 (10)	24.7 (4.7)	6.67 (4.8)
CR-Social Dysfunction (Range:40-200)	107.3 (42.4)	144.4 (32.6)	80.7 (24.2)

CR=Care-recipient; C=Caregiver

Dementia Subtypes: bvFTD and EOAD

This EOD care-recipient sample is heterogeneous in symptomology; this is consistent with their dementia diagnosis subtype of either EOAD or bvFTD. The differential diagnosis within this EOD sample can explain the wide variation of scores in the scales reporting of the care-recipients' impairment. Thus, accounting for the dementia subtype provides a more accurate description of this EOD sample when calculating the degree of impairment. This is especially important in dementia because the diagnosis criterion for each EOD subtype relies on specific domains of impairment, which may be indicators for the specific region of the brain that may be involved. Additionally, there are no differences of disease duration EOD. The bvFTD mean years since disease onset is 2.9 (± 1.1) while the EOAD is 3.8 (± 1.9).

Disease severity was not easily determined using the conventional measure of cognition. Both groups are similarly cognitively impaired based on the MMSE, which is the most commonly used global cognitive test. However, the bvFTD care-recipients had a more advanced disease stage based on the Clinical Dementia Rating Scale (CDR); the bvFTD care-recipients global score of 1.1 (± 0.4) is considered mild to moderate dementia while the EOAD score of 0.7 (± 0.3) is considered very mild-to-mild dementia. However; Deutsch et al. (2016) reported on this sample and found that the Frontotemporal Lobar Degeneration (FTLD) CDR, which includes additional language and behavior items, is a better measure to compare severity between these two EOD subtypes (Deutsch et al., 2016). Hence, on the FTLD-CDR, the bvFTD care-recipients have greater overall disease severity; however, in the memory subdomain the EOAD subgroup was statistically more impaired.

Additionally, the bvFTD care-recipients had persistently greater functional, psychiatric, and emotional impairment compared to the EOAD. The bvFTD and EOAD care-recipient

groups are both functionally impaired per the FAQ, with both exhibiting a score above the 9-cut-off point, 19.2 (7.0) versus 11.3 (7.0) respectively. However, the bvFTD had statistically significant greater functional impairment than the EOAD sample.

The bvFTD care-recipients also had a greater number of psychiatric and emotional symptoms compared to EOAD care-recipients. Per the Neuropsychiatric Inventory (NPI), bvFTD care-recipients had a greater number of psychiatric symptoms at a greater frequency than EOAD care-recipients (see Table 4 below). Specifically, bvFTD care-recipients exhibited more agitation, anxiety, euphoria, apathy, disinhibition eating related behaviors and aberrant motor behaviors than EOAD. In comparison, the EOAD population was significantly more likely to be severely depressed.

Lastly, there is great disparity on emotional responsiveness between both dementia subgroups. The bvFTD care-recipients were significantly more emotionally blunt with an Emotional Blunting Scale (EBS) score of 24.7 (4.7), which is above 19, a score often seen in psychiatric care-recipients.

Caregiver's Emotional Profile

The caregiver may experience burden and emotional distress according to data provided on the caregiver specific scales (see Table 3). Caregivers in this EOD sample report a mean Zarit Burden Index (ZBI) score of 36.9 (± 19), which is well above the standard cut-off score of 24 that indicates a distressing level of caregiver burden (Schreiner et al., 2006). They are depressed compared to norm rates of the population with a Center for Epidemiological Studies-Depression (CES-D) mean score of 14.9 (± 11.6), a mean score above the normal range (6.9-9.1) in young adults (Blazer, 1994). However, they are below the cut-off score of 16, which indicates risk for clinical depression (Weissman et al., 1977). Additionally, caregiver responses to the NPI-Distress

scale indicate they experience great distress due to care-recipient behavioral problems (Table 4).

Table 4: Neuropsychiatric Inventory Caregiver Distress Scores						
NPI-Behaviors Care-recipient	EOD (n=29)		bvFTD (n=13)		EOAD N=16	
	N	mean(SD)	(N)	mean(SD)	(N)	mean(SD)
Hallucinations	3	4.0(1.0)	3	4(1.0)	0	--
Agitation	12	2.9 (1.4)	7	3.4 (1.4)	5	2.0(1.3)
Depression	10	3.2 (0.9)	2	2.5 (0.7)	8	3.4 (0.9)
Anxiety	13	2.2 (1.3)	4	3.0 (0.8)	9	1.9 (1.4)
Euphoria	5	3.4 (2.1)	5	3.4 (2.1)	0	--
Apathy	21	2.7 (1.4)	11	3.0 (1.3)	10	2.4 (1.4)
Disinhibition	12	2.8 (1.5)	9	3.0 (1.6)	3	2.0(1.0)
Irritability	13	2.8 (1.2)	4	3.5 (1.3)	9	2.4 (1.0)
Aberrant Motor Behaviors	19	2.1 (1.3)	11	2.3 (1.3)	8	1.8 (1.4)
Night Behaviors	11	2.3 (1.6)	5	3.4(1.5)	6	1.3 (0.8)
Eating Behaviors	15	2.6 (1.3)	10	2.8 (1.1)	5	2.2 (1.6)
Delusions	4	3.8 (1.3)	3	4.3 (0.6)	1	2.0 (0)
NPI Total Caregiver Distress	5	14.8 (11.6)	7	20.6 (15.0)	4	10.1(5.0)

Disease Subtype and Caregivers' Emotional Status: bvFTD and EOD

The differential symptomology by the dementia subtypes also has an impact on the caregiver (see Table 3). The bvFTD caregiver reports statistically significant greater depression than reported by EOAD caregivers. The mean score on the CES-D for the bvFTD caregiver group is 20.4 (\pm 13.2), well above the cutoff score of 16 and considered at-risk for clinical depression. The EOAD sample, although below the cut-off score for clinical depression, is well above that of the general population with a score of 10.5 (\pm 8.1). There is also a difference of total burden between the bvFTD and the EOAD caregivers based on the ZBI. Both groups are undergoing caregiver burden with scores well above the cut-off score of 24. However, the

bvFTD caregivers report greater total burden than that of EOAD caregivers. The bvFTD caregivers report over 30 percent more burden than EOAD caregivers with a ZBI mean of 44.3 (± 22.7) vs. 31.4 (± 15.4) respectively. The difference is statistically significant. The bvFTD caregiver group expressed significantly greater overall NPI caregiver distress compared to the EOAD (20.6 (15.0) vs. 10.1(5.0) (see Table 4).

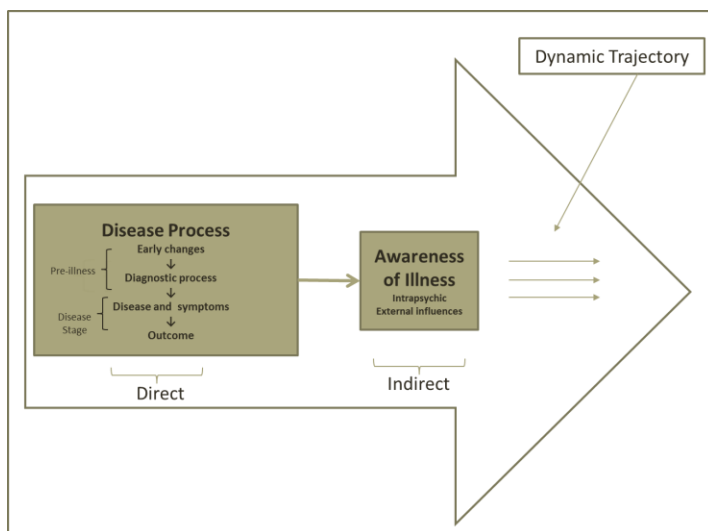
Chapter Summary

In sum, in this EOD sample the care-recipient demonstrates great impairment with detrimental outcomes for the caregiver. Furthermore, there are significant differences in the dementia subtype where the bvFTD care-recipient had greater impairment resulting in a greater burden of distress for caregivers. The following chapters will describe in detail the factors that may contribute to these outcomes. The next chapter titled, “Chapter 4: The OED Caregiver Illness Course,” describes dimensions of the illness that are primary stressors for caregivers.

Chapter 4: The EOD Caregiver Illness Course

The illness course encapsulates the effects of the disease on care-recipients (disease stream) as well as the emotional responses the presence of the disease elicits on caregivers (see Figure 2)—it is the detailed illness trajectory mechanism (grounded theory) described in Figure 1. Within the overall caregiver experience, the illness course is the principal and most proximal process affecting caregivers. The illness course includes two major categories: (1) the disease process and (2) the disease-focused response of caregivers. The first captures the disease process itself, which is the direct patient experience due to the symptoms and changes related to the dementia. These are illness-related components, are the major driving forces in the cumulative dementia caregiver experience. Specifically, it refers to the situations generated from the care-recipient’s dementia-related changes or “symptoms” that develop by the presence of the disease. The disease process also generates indirect non-caregiving-related factors through a task multiplication mechanism. This is addressed in more detail in Chapter 5 where the caregiver course is described.

Figure 2: Illness Trajectory



The indirect component emerging directly from the “disease stream” refers to the disease-related response of the caregiver. This is the second major category in the proposed illness trajectory. The disease-related response describes the indirect emotional consequences of the disease as experienced by the caregiver. The caregiver is the second key participant in the caregiver-illness trajectory—the care-recipient being the primary. The caregiver “awareness of illness” component describes the caregiver feelings that may arise due to the dementia-related changes observed in the spouse.

The Disease Process

The various stages within the disease status will help shed light into the care-recipient’s illness course and the corresponding emotions the illness elicits in the cumulative caregiver experience. The awareness of the disease process is linear with four major stages: (1) pre-illness early changes, (2) the diagnostic process, (3) redefining disease and symptoms, and (4) anticipating final illness outcome (see Figure 3). The first two stages may occur at pre-illness or prior to obtaining a medical diagnosis. During the “pre-illness early changes,” some caregivers first observe disruptive behavioral, emotional, or memory changes of the care-recipient. The recognition of these changes may lead them to seek help from the medical establishment not only to understand the reason for the changes but also to initiate the “diagnosis process.” The diagnosis process can be very particular in this EOD population where, due to the atypical nature of the disease, the care-recipient and caregiver will navigate a lengthy process with multiple providers before they can obtain a final diagnosis. The “disease symptom” stage covers a plethora of disease symptoms that are then labelled as disease after receiving a formal dementia diagnosis. Lastly, the prognosis or progression to the severe and/or terminal stages of dementia is something that the caregivers are aware will occur. At some stage in the disease process they

may start to plan for end-stage illness and begin to deal with their feeling of grief and loss (discussed in Chapter 8).

Pre-illness Early Signs

The “Pre-illness Early Signs” stage constitutes the initial changes that alert the caregiver that there is a shift in the care-recipient’s normal behavior or degree of function. This stage of the illness trajectory is the time before a medical professional confirms a dementia diagnosis. In this EOD study sample the “Pre-illness Early Signs” stage includes three major sub-categories: a “premorbid function,” “awareness of early decline,” and the “disruptive incident.” The caregiver may notice that there is something different or not right about the spouse whom they know well. The early changes within this stage involve subtle changes or decline in their spouse’s behavior, memory, and function. This initial stage will often culminate in a disruptive event or incident of the care-recipient, which prompts caregivers to seek medical help. Recognizing the existence of this early stage helps understand the caregiver trajectory because it establishes when caregiving may have started and provides information on how long caregivers may have been dealing with caregiver types of issues.

Premorbid Status

Many caregivers describe the observed changes in their spouse by comparing how they were before the illness—coded in this study as “premorbid status.” Specifically, these caregivers reference back to the “pre-morbid” status to explain why they were alerted that something was not right during the “early changes” phase, prompting them to get help. The premorbid attributes described by EOD caregivers may include a description of their spouse’s personality and/or cognitive or functional abilities at the workplace and at home. Additionally, some caregivers continuously reflect about the person they knew before the illness to better understand or explain their

present situation.

For the most part caregivers report that, prior to the dementia changes, their spouse carried out their roles quite well within the workplace. They describe them as doing an overall excellent job and getting along well with others.

065-02-01: "A little disorganized, but really good at his job. A great writer." [56-year-old female caregiver]

065-01-07: But anyway-she always had a lot of friends-always outgoing, loved shopping, going out with girlfriends, going out with couples, going to different things. [67-year-old male caregiver]

Additionally, before the illness their spouse may have been good contributors to the household. They actively participated in the household and successfully fulfilled their role as parent and spouse.

065-01-14: "He was a very good husband and was a phenomenal father." [52-year-old female caregiver]

Some caregivers describe the premorbid state based on the care-recipient's prior social interactions with others. They recalled that the care-recipient had a successful social life before the disease.

065-01-08: "He was very, very social with people in his field and the business world. He was very popular as a consultant, very creative, especially when he was teaching in the [prestigious university] Business School. He was involved in those tea groups." [73-year-old female caregiver]

Many commented on the personality traits of their spouse as they remembered them before the onset of the disease. Although some of the traits described by the caregivers varied on pleasantness, it was particularly important for caregivers to establish that the care-recipient had a different personality prior to the disease. The person they knew before the disease may have been a very different person than the one they have become.

065-01-06: "Very opinionated. Very much so. When he knew that it was the right thing, he stressed that, you know, "You're wrong." If somebody said, "really, the sky has no color." He'd

say, "No. The sky is blue. If you look at it, it's blue." [50-year-old female caregiver]

They also highlight the care-recipients' pre-morbid functional and cognitive abilities. Per the caregiver, their spouse, for the most part, was very efficient and often excelled in their profession. Some described them as having been highly organized and productive in their daily lives.

065-02-28: She was energetic. She was – her daily routine would be get up at 4:30 in the morning, prepare herself get a little hot drink of some sort, have some breakfast and she would leave by 7:00, drive 30 minutes to work, to school, get there a half hour early and she would probably spend about an hour there after school and then come home and spend maybe the next 2-3 hours at the table correcting her papers and that sort of thing. [66-year-old male caregiver]

Furthermore, some care-recipients were described as perfectionist and meticulous. The caregivers outlined their attributes and stated that they excelled in various cognitive tasks.

065-01-06: Very fine-tuned vocabulary was a big issue for him, especially with me. If I used a word out of context he would very much bring it to my attention, whether it be in front of people or not. "You shouldn't be using that type of word that way. It doesn't go in that context." Pronunciation, punctuation, and writing. [50-year-old female caregiver]

There is a pronounced contrast in the care-recipient's cognitive ability at the early changes stage. Caregivers describe these changes by drawing a comparison between how their spouse was before the illness and how they are now. The change typically occurred in a relatively brief period, from months to a year before a formal diagnosis.

065-02-30: A year ago, nine months ago, I could always understand what he said. Almost every sentence there'd be a word that he'd mispronounced one syllable, or he'd use the wrong word, or he'd forget the word and have trouble trying to remember it, but I'd always understand what he meant. [48-year-old female caregiver]

Disease Subtype Differences

There may be differences in the early symptom stage for care-recipients with bvFTD compared to those EOAD. Specifically, some caregivers reported differences in level of awareness to these early symptoms by the care-recipient based on their dementia subtype. Those caring for a spouse diagnosed with EOAD found them to have greater awareness of their early changes, unlike those caring for a spouse diagnosed with bvFTD. However, in both instances the

caregiver notices early in the process that something is not right and becomes instrumental in detecting new issues and seeking medical assistance.

In EOAD, the early symptoms or indicators range from the common memory symptoms in dementia such as misplacing items, not remembering dates, to the inability to perform routine work and home tasks. Commonly, caregivers describe the changes in care-recipient's cognition as impaired "thinking" or "memory" problems. In these instances, the caregivers report that the care-recipients are for the most part aware of their own cognitive decline.

065-02-01: It took a long time. He complained of memory and thinking problems for a long time before anyone believed him. [56-year-old female caregiver]

On the other hand, care-recipients with a bvFTD diagnosis are not aware of these changes due to decreased insight, a symptom of the disease. Hence, others mainly observe the "early changes" around them, particularly their spouse. Per the caregiver, care-recipients do not express much insight into their changes and cannot be depended on to alert or react to the initial stages of the illness. Some changes may involve decreased function, but unlike the EOD, the sufferer may be less likely to be self-reflective about it.

065-01-06: I would be like, "[The care-recipient name], you've done this all along. It's really a quite simple task. Why are you changing it up now?" Part of it was, he would, he really wouldn't make an excuse, he would say, "well if they would quit changing things." Like putting the blame on the office. I'm like, "they didn't change any of this." [50-year-old female caregiver]

The early changes in bvFTD also include alterations in the care-recipient's behavior and personality.

065-01-06: You know. And then, not the glazed, glassy look effect anymore, it was the repetitive—repetitive was really noticeable, and then started the repeating and "Something's still not right." [50-year-old female caregiver]

As caregivers reflect on early changes in bvFTD they report that behavioral changes may have started even many years before changes were first observed—and an even longer time from when they started to seek a formal diagnosis. Caregivers may have been dealing with and

managing the changes of the care-recipient for a substantial length of time.

065-01-38: So anyway, I lost about a year of time getting an early diagnosis because of resistance of the primary care physicians to finally get some proper treatment. From that point on, the neurologist saw us back 4 months later, and since he was not a specialist he threw up his hands and says, 'what am I going to do about you guys?' [70-year-old male caregiver]

Disruptive or Alarming Incident

These early changes almost always culminated with a “disruptive or alarming incident” that may have prompted the family or more commonly the spouse to seek formal medical care. This event is the first noticeable indication of the severity of the dementia situation. These incidents are also defined by the dementia subtype, EOAD versus bvFTD. These early events foreshadow the future when the care-recipient may become unable to function independently.

065-01-14 That was the beginning of the end. They went on a bike ride. He rides his bike every day. He told [our oldest daughter] he wanted to go on a bike ride, she was following him, and he disappeared on this bike path. [My oldest daughter] lost him, she called the police, and the police finally found him almost 20 miles from where they started, he was totally disoriented, he was dehydrated, and they were like, "There's some kind of problem." [52-year-old female caregiver]

Those care-recipients providing care in EOAD report incidents that are consistent with early changes in memory and cognition. These incidents may involve subtle changes in the EOAD care-recipient's ability to function in their work and other life domains. For example, in the workplace, the care-recipient's employment is compromised due to their decline in cognitive ability, limiting their ability to perform their work. These noticeable, yet gradual incidents also prompt caregivers to seek a medical evaluation in EOAD caregiving.

065-02-45 She was working part time on the cruise ships, changing people's credit cards onto ship's credit cards. And it was kind of...made a few mistakes when she was having the memory problems, and she wasn't doing everything she was supposed to be doing and they corrected on her twice and said hey, we have to take you off because this has to do with security and this has to be done. [65-year-old male caregiver]

For the bvFTD caregivers, the determining incident was often associated with changes in behavior and personality. These were incidents that may have compromised the care-recipients' employment as well as other domains in their lives. Additionally, in bvFTD, these incidents were

often due to impaired social interactions with others. Specifically, job-related early changes in bvFTD are due to inappropriate interactions with co-workers, customers, or supervisors related to inappropriate behavior and changes in personality. These leads to noticeable changes in work performance of the bvFTD care-recipient by others.

065-01-08: They [people at work] were noticing that he didn't respond—the same thing that I noticed—the thought process was being delayed. That he was slow in answering, that he was not able, in the classroom discussions, to have a lively give-and-take, which he was excellent at. [73-year-old female caregiver]

This is also the case at their home where changes in the care-recipient's behavior alters the relationship with their family and friends. The care-recipient often embarked in major uncharacteristic and alarming life changes.

065-01-08: There was one time, in 1982 where, out of the blue, he accused me of not being "mod" enough. Of not being enough of a partier, and plain old stupid, you know. And eventually moved in with a doctoral student from public administration, and then made her a research associate. It was just a whole big mess. [73-year-old female caregiver]

Diagnosis Process

The “early changes” greatly alarm caregivers such that they seek medical care to initiate a “diagnosis process,” entering the second phase of the disease process. The diagnostic stage in EOD is characterized as a lengthy and stressful process for both the care-recipient and caregiver. EOD is a rare illness, and most general providers lack the experience to properly diagnose patients.

The diagnostic challenges are distinct for EODs compared to the common late-onset dementias because of the atypical early age of onset and because the symptomology may mimic a psychiatric disorder (Mendez, 2006).

065-02-19: So we pursued that for a month or two, and he was having the panic attacks, and then I had him go see my psychiatrist. I'd known them for years, they know me, and they know the whole situation. It's like hitting the ground running. The geography wasn't ideal, but they could get him that day, they would do that for me. So I already had the relationship, so he started seeing my psychiatrist, who still wanted him to see a psychologist for counseling. Which he did. So the

psychiatrist got him on Wellbutrin, got him to stabilize some of the anxiety behavior, and the panic attacks, and the not sleeping. [50-year-old female caregiver]

Hence, in EOD the diagnosis process is long and strenuous because the care-recipients are commonly misdiagnosed. Additionally, due to the rarity of the disease, care-recipients are often mismanaged—frequently they are inappropriately referred to specialists.

Additionally, although this population is not elderly, primary care doctors can mistakenly identify the disease as a natural aging process.

065-01-06– Then [our primary care doctor] said, “It’s definitely not Alzheimer’s, [wife’s name].” he said, “but something’s not right. So, let’s just observe. It could just be normal aging process, let’s see what’s going on.” [50-year-old female caregiver]

Providers may have also assessed the symptoms as the care-recipient undergoing a “middle-age” crisis; this is particularly true in bvFTD who exhibit major changes in personality or behavior. In both instances, the provider may not consider additional evaluation or follow-up to be necessary. The caregivers are sent home without any help; however, they often return because the symptoms worsen and the situation becomes unmanageable for them.

065-02- 29 Yeah, he went to our family doctor, and I think he even did an MRI on him and everything was fine. Then I think after a while he sent us to a neurologist, I think he did an EEG and everybody said everything was fine all the time. But more and more things were happening so. [55-year-old female caregiver]

A care-recipient with psychiatric symptoms adds diagnostic barriers and challenges for a typical provider. They often misdiagnose them with a psychiatric disorder, which may then initiate a course of psychiatric treatment that may be ineffective. For example, care-recipients with depressive symptoms, typically EOAD care-recipients, are treated with anti-depressive medication.

065-02-19: So we thought, because I was going through the cancer, that it was depression. We were trying for a period of time to get him some counseling help... so he started seeing my psychiatrist, who still wanted him to see a psychologist for counseling. Which he did. So the psychiatrist got him on Wellbutrin, got him to stabilize some of the anxiety behavior, and the panic attacks, and the not sleeping. [50-year-old female caregiver]

Their decline in cognitive function may be aggravated by the depression because they usually have some insight into their decline.

065-02-19: The hardest thing is loss. You were saying, it's hard for [my husband] 'cause he's aware of it, and it's like, we're going through this together, and every day, it's so painful. I'm glad that we have time together, and we still have fun, but I can't logically depend on him. It just isn't there. [50-year-old female caregiver]

EOD care-recipients are also often misdiagnosed with a range of conditions such as alcoholism and schizophrenia. Additionally, the care-recipients with greater behavioral impairment, common in bvFTD, are frequently medicated to help manage disturbing behaviors. However, most treatments may be, in the long-term, ineffective due to the progressive and degenerative nature of the illness.

Thus, even though caregivers may be offered help to manage the care-recipient, they continue to perceive that something else may be going on and insist on pursuing a proper diagnosis. The caregivers are often the ones who are most persistent in obtaining a diagnosis; they become relentless advocates for the care-recipients.

065-01-06: So it took a little bit of persistence, on my part, as to pushing the issue: something's going on. And I think--from seeing and hearing other things, and reading other things, even with Alzheimer's patients, too--it takes that family persistence, that there's something going on. And some people--I can understand that they get frustrated and "listen to me!" [50-year-old female caregiver]

They often question the initial diagnosis, which may not align with their own experiences or daily interactions with the care-recipient. Caregivers may challenge the original diagnosis as well as the providers and their medical opinion.

065-01-06: "Something's really going on. Something's not right." Then it took, we did PET scan, and there were just other little things, and I just kept pushing the issue, "Something's not right. Prove to me it's alcohol. What can we do?" "Even if it's, [the patient's name], get down here. We need to do urine, blood, or whatever tests". [50-year-old female caregiver]

Although there is no cure for dementia, most caregivers express respite when they eventually obtain a diagnosis. Principally, they feel validated in their knowledge of the care-

recipient changes and disturbances. Additionally, they are now able to label or name the disruption in their lives. A diagnosis frees them up to move within the illness trajectory so that they can focus on the management of the care-recipient needs and their own readjustment to the disease. At that point, caregivers start to focus on accommodating their lives to their present situation, which has been uprooted by the disease. This adjustment process is discussed in more detail in Chapter 7, “Caregiving as a Trajectory.”

Disease and Symptoms

As they overcome the challenges posed by the diagnosis, caregivers may begin to understand the realities of the disease. This reality entails the worsening of “early symptoms” and new symptoms developing along the course of the illness. The EOD caregivers are dealing with a dementia sample with distinct and varied symptomology based on their dementia subtype, i.e., EOAD versus bvFTD. The type and the severity of the symptoms may define the caregiver tasks and directly affect the degree of the physical and emotional burden experienced by the caregivers.

EOAD care-recipients may display great decline in memory and in mood, such as depression. For the EOAD care-recipient, the dementia- related memory decline interfered with their ability to carry out many of their previous activities. Specifically, their memory decline affects their capacity to carryout simple routine tasks in their household such as cooking, cleaning, or maintenance. Hence, the care-recipient is gradually unable to carry out most of their household duties and eventually loses their ability to perform the basic activities of self-care.

065-02-29: Just simple things like that are getting harder for him. He can't read directions or anything, because he doesn't retain it. I usually make him lunch or something when I come home, and I usually do most of the cooking.” [55-year-old female caregiver]

Those EOAD care-recipients with depressive symptoms often demand greater time and attention

from the caregiver. The depressive symptomology affects the interpersonal relationship between EOAD dyad; the care-recipient may not initiate activities and may emotionally withdraw from others.

065-02-45: Not really. It's just it...when she's feeling bad, she just wants to lay down. So she just stays in bed and says I'm just tired. I just don't want to get up. I'm tired. I don't feel right. I'm just tired. And I can't get her up to make her feel better. I can't do anything to make her feel better or to get her out of bed. And... that's the hard part, too. Get her motivated to do something is just sometimes, it's just impossible. She just wants to sit there until she feels that she's okay. [65-year-old male caregiver]

Hence, EOAD caregivers providing care to depressed individuals undergo greater burden because, beyond dealing with the care-recipients' memory deficiencies, they also deal with the depression-related symptoms.

In bvFTD, like in EOAD, the caregivers also describe impairments in the care-recipient's capacity to carry out social interactions. However, the behaviors disrupting the social interaction are different; in bvFTD the care-recipient does not respond or contribute appropriately to routine daily conversation. The conversation becomes one-sided where caregivers may not be able to sustain normal conversations with the care-recipient.

Furthermore, these social interactions between care-recipients and caregivers are also compromised by impaired conduct, such as repetitive behaviors and inappropriate acts. The care-recipients may display strange behaviors that are disruptive in their daily interpersonal interactions.

065-01-34: He sees anybody on the street, the mailman, and he hovers over them. He has no personal space. He has to go out to talk to them, and he tells them the same thing over and over again. [42-year-old female caregiver]

Some of these behaviors may become unmanageable for caregivers. Some of these acts are disruptive—such as obsessive-compulsive behaviors—that make the caregiver to feel distressed.

065-01-42: Her memory, she'll remember an actor or somebody maybe more than I will, but the behavioral side of it is just bizarre, and the conversational side of it. When we are driving in the

car the depth of her conversation is, the license plate, whether her son is in the car, a billboard, a repetitive thing – I know when we go by a certain thing that she's going to make a comment on it, and it's going to be the same comment. [74-year-old male caregiver]

Another major disturbing behavior in bvFTD is the care-recipient's inability to emote, which greatly impairs the emotional connection with the caregiver as well as with others.

065-01-07: She's totally non-emotional anymore, anytime now. [67-year-old male caregiver]

The emotional blunting may limit the care-recipient's ability to display a normal exchange of affection. The caregiver may find themselves interacting with a spouse that cannot emotionally reciprocate.

065-01-34: And he can't. He can't cry. That was another thing that I started to notice. He didn't cry a lot, but he cannot produce tears. I don't know why. I even told the doctors that, because when somebody can't show that emotion I'm thinking 'there's a problem.' He can't produce any tears. He'll be sad for a minute, then it's like he turns it right off. [42-year-old female caregiver]

Lastly, the care-recipient may also exhibit a change in personality due to the dementia. Often this results in new and unpleasant care-recipient attributes that negatively transform the caregiver's living situation.

065-01-14: He's not argumentative, he's not confrontational. Sometimes he can be mean by the way he says things, but he's not outwardly mean or abusive or if anything he's more passive aggressive. [52-year-old female caregiver]

These changes or symptoms directly affect the caregiver's workload where they must pick-up the care-recipient's share of the household responsibilities. The spousal relationship can become gradually unilateral; caregivers increasingly assume most of the household workload. This is discussed in further detail below and in Chapter 5, "Caregiving in Early-onset-Dementia: Caregiver Tasks and Emotion."

Caregiver Acceptances of Illness

The disease trajectory prompts a process of caregiver awareness, which is a secondary caregiver stressor proliferating from the presence of the disease and its symptoms. This

awareness was often brought on by the caregiver's own feelings and knowledge as well as external opinions and biases that influence their emotional response to the illness. This gradual awareness is what forces some caregivers to accept the illness as a part of their life.

However, the degree of acceptance of the illness by dementia caregivers varies. Furthermore, acceptance of the illness is not static. Caregivers will fluctuate in their degree of awareness; while caregiving they may opt to confront only certain aspects of the disease at different times. Hence, a caregiver's description of the illness can vary from accurate to a distorted assessment of the care-recipient's impairment. The variability may depend on where they are in their caregiver trajectory. The caregiving trajectory is described in more detail in Chapter 7, "Caregiving as a Trajectory."

Avoidance

The caregiver's lack of disease awareness or avoidance may lead caregivers to have unrealistic expectations of the care-recipient's function. It also shields them from confronting the full reality of their situation. Caregivers are in a constant inner struggle between the necessity to provide care for the care-recipient and the need to manage their emotional status to avoid aspects of the illness they are not prepared to confront and/or accept.

Therefore, avoidance of the care-recipient's actual illness situation can be a positive coping mechanism for the caregiver. It allows caregivers the ability to maintain normal expectations from the relationship as they attempt to maintain the normality of their pre-illness life. They struggle because caregivers are not ready to give up the person they knew before the disease.

Hence, caregivers use different approaches to sustain a manageable life within the realities of the illness. They continually re-interpret what the care-recipient is feeling so that it

aligns with their pre-illness life. In the case of bvFTD care-recipients, they may opt to interpret emotional responses from their spouse although the care-recipient may be emotionally blunt. This helps them ease the distress generated by the emotional emptiness they now encounter in their spouse. They also look for the emotional interchange they had before the illness with their spouse. Often, the caregiver fabricates these perceptions in order to cope with their illness situation.

065-01-03: Yes, and I guess my problem's also to keep, to stop projecting myself into his situation. If he looks a little sad around the eyes as sometimes he seems to, I still have to convince myself against appearances, I guess, that this does not mean that he is feeling miserable and seeing his life trickling out like as many grains of sand.

While in EOAD, caregivers enable the care-recipients' memory deficiencies to maintain a perception of normality, particularly around others. Maintaining this perception keeps them from confronting or grieving for the eventual loss of their pre-illness life.

In addition, caregivers may interpret their spouses' behaviors based on recollections of their pre-illness level of function to hold on to their prior life or to the spouse they knew before the illness. This means that the caregiver maintains a distorted assessment of the situation as a coping mechanism. This altered view of the care-recipient's ability is a necessary phase in the caregiver trajectory. However, caregivers may encounter circumstances where they may not be able to avoid the reality of their situation and their attempts to normalize the situation may fail. This may lead caregivers to experience frustration.

Anger

There may be anger associated with the awareness of illness. The anger may stem not only from the care-recipient's illness-related behavior and actions but also from the caregiver's own inability to accept and readjust to the changes generated by their spouse's illness.

065-01-14: And yet there are moments that I'll lose it, because I've asked him to do something to help me and he's forgotten or just decided he doesn't want to do it, and I know it doesn't do any

good, but there are sometimes where I'm like, "You've got to try, you know, I know it's hard for you, but you've got to try. [52-year-old female caregiver]

Anger due to the caregiver's failure to accept the care-recipient's decline contributes many frustrations in their daily interaction with the care-recipient. Essentially, caregivers experience frustration when the care-recipient fails to perform up to their unrealistic expectation.

Acceptance of the disease and its consequences is not easy for the caregiver because it implies a full understanding of the impact of the illness that includes their spouses' continued impairment and eventual death. Acceptance will initiate anticipatory grief, a type of grief experienced by caregivers while they are actively caregiving, see Chapter 8, "Caregiver Grief in Early-onset-Dementia."

065-01-42: "There's always things that could be worse, but this is the worst I ever thought it was going to be." [74-year-old male caregiver.]

Complete acceptance of their present reality may compromise the caregiver's ability to "keep going" or to sustain their daily caregiver duties.

External Factors

There may also be external factors influencing the caregiver's emotional awareness of the illness. The caregivers endure the stigma due to others perception of the disease.

065-01-06: It's not fair to him because he's still able to function. But when people noticed, like, little oddities in 2008--we were doing medical testing and everybody was so, "Oh, poor [wife's name]. Poor [patient's name]. I hope everything works out."

Additionally, they often experience embarrassment due to distressing changes and the rarity of disease.

065-01-14: I know he doesn't look like it, but my husband has dementia." And he was like, "Oh yeah right, what is your husband? 55?" and I'm like, you know, "You're such an a ____." [52-year-old female caregiver]

These external factors influence the caregiver's internal feelings towards the illness and their ability to accept it.

In sum, caregivers may be undergoing an internal emotional path of illness acceptance as they manage the disease. In response to the care-recipient's changes, there are many internal factors that contribute to the caregiver's feelings as they struggle between acceptance and avoidance.

Chapter Summary

The illness trajectory is a dual process where what the care-recipient is experiencing has a direct effect on what the caregivers feel. To have a comprehensive understanding of the EOD illness trajectory, it is necessary to account for the following: (1) what the care-recipient may be experiencing due to the disease, (2) the care-recipient's changes, and (3) how caregivers deal with the feelings that arise from the presence of the illness. The ability to understand these three aspects will help assess where the caregiver may be within the caregiver trajectory. Accurate disease staging is particularly important for EODs due to variability of symptoms and its rapid progression. Furthermore, this knowledge may help indicate effective areas and timing of interventions for EOD caregivers.

Chapter 5: Caregiving in early-onset Dementia: The Caregiver Stream

This chapter aims to obtain an accurate glimpse of the complexity of providing care to this EOD population. Although the “illness trajectory” described in Chapter 4 is an important stream within the multiple the total caregiver experience, the “caregiver stream” is crucial to understanding the most modifiable aspects of the caregiver experience. The caregiver stream described in this chapter illustrates what EOD caregivers do in their role and explains the emotional impact these tasks may have on these young spouse caregivers. The “caregiver stream” parallels the disease stream identified above and captures caregiver-specific issues that may affect the overall EOD caregiver experience; the caregiver stream involves not only proximal caregiver tasks (i.e., helping with ADLs) but also distal life-related tasks (i.e., employment and parenting) that are compounded by EOD caregiving. The caregiver stream is summative of all caregiving and non-caregiving related demands that the EOD spouse caregivers may confront while caregiving.

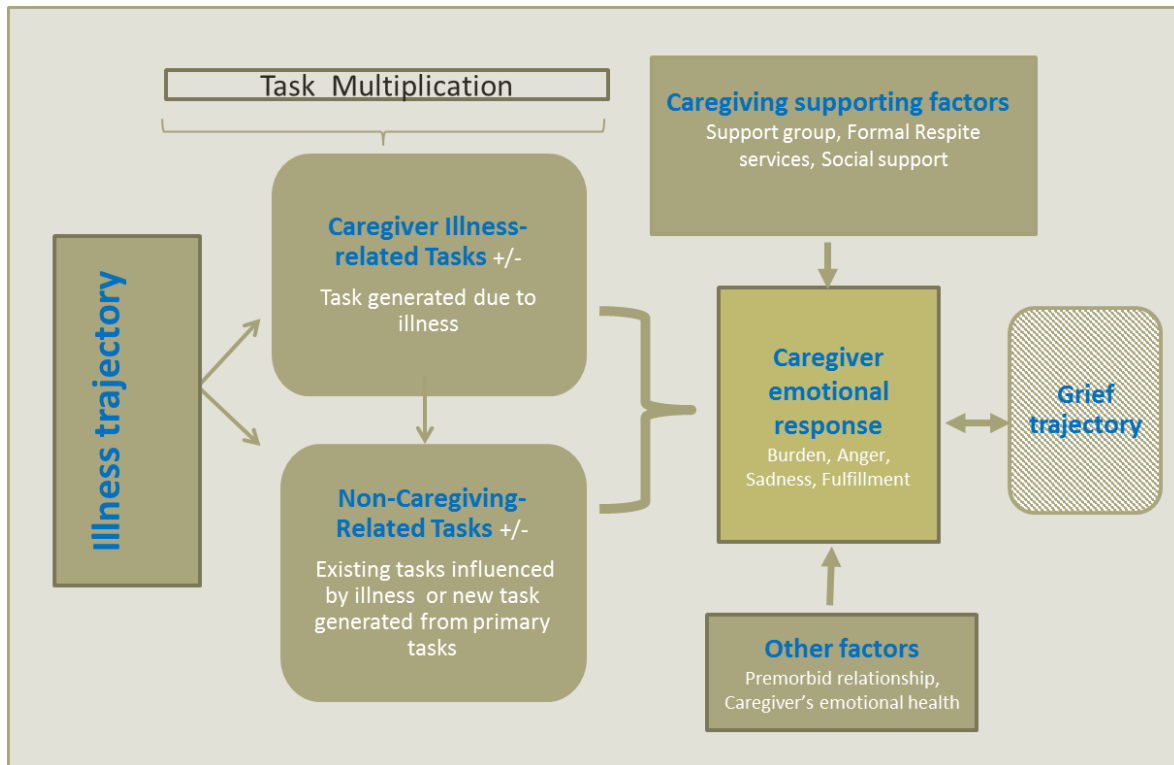
The caregivers in this sample describe their caregiver illness-related tasks as those directly emerging from the decline in the care-recipient’s function, behavior, and cognition. Additionally, they describe added demands, or non-caregiving-related tasks that are generated from these illness-related tasks. This concept of task multiplication is similar to caregiver stress proliferation construct presented by Pearlin and colleagues (Aneshensel et al., 1995; Pearlin et al., 1997; Pearlin et al., 1990); yet in the proposed task multiplication model, the outcomes may not necessarily result in added stress for the caregiver. The task multiplication model disassociates stress from caregiving tasks to incorporate other positive or manageable caregiving outcomes in addition to stress. Hence, the task multiplication model is not a substitute but expands the stress proliferation model by incorporating positive aspects of caregiving that may

buffer or alleviate stressful aspects of caregiving.

The stress proliferation model is based on the concept that stressors do not manifest in isolation but interact with existing stressors (Pearlin et al., 1990). The task multiplication model similarly considers that caregivers engage in multiple compounding tasks; however, not all tasks are negative and some may even be rewarding for caregivers. Since these tasks may occur concurrently during caregiving, caregivers may perceive them as competing demands that may result in greater strain, or they may be buffers that provide respite. Thus, the concepts set forth in the stress-proliferation model continue to be relevant because, similar to the proliferation of caregiving stressors, new tasks may be generated (Pearlin et al., 1997). However, the manner that caregivers experience these caregiving-related tasks is contingent on many other issues in their lives (i.e., contextual factors). Hence, expanding the stress proliferation model may better explain the observed divergent reactions across caregivers to the same direct caregiving tasks or similar illness trajectories. It can also identify positive areas in caregiving that may inform interventions to ameliorate the caregiving experience.

Caregiving for EOD entails the interaction among the physical, social, and emotional tasks combined with caregiver resources. The EOD caregivers in this sample describe caregiver tasks that are linked directly or indirectly to the dementia: illness-related and non-caregiving related tasks (Figure 3). The “illness related tasks” are new tasks resulting directly from the illness trajectory. The “non-caregiving-related tasks” refer to both new and existing non-caregiving tasks that are aggravated by the illness trajectory. Both types of tasks may alter, positively or negatively, the caregiver’s emotional response. In addition, supportive caregiver factors may also help also mediate the overall caregiver situation.

Figure 3: EOD Caregiver Framework



Caregiver Illness-related Tasks

Caregiver illness-related tasks refer to issues emerging directly from the presence of dementia. They may be tasks that developed in response to symptoms or the unattended tasks the care-recipient is no longer able to perform and the caregiver must now assume. The illness-related tasks include providing chronic vigilance of the care-recipient, uptake of their household tasks, and assistance with employment and interpersonal relationships. The illness-related tasks occur mainly within the household but can also involve the care-recipient's social and employment domains.

Chronic Vigilance

Chronic vigilance is the prevailing caregiving illness-related task. It involves continued watchfulness or alertness of the care-recipient in response to their disease-related symptoms.

065-02-01: Feel like I need to be available in case he needs me or has questions. [56-year-old female caregiver]

The observed chronic vigilance by the caregiver is twofold. The first is the direct watchfulness of the care-recipient. The second is the less observable, yet just as impactful, constant preoccupation for their spouse's safety and needs. Chronic vigilance elicits a status of continuous hyper-alertness for the caregiver. This vigilance is in response to the potential dangers their spouse may be vulnerable to due to the illness. Caregivers have a profound sense of responsibility for the care-recipient's safety, which results in a continued status of concern. The intensity of the chronic vigilance may vary throughout the caregiver experience, principally determined by where the care-recipient is in their illness trajectory and the disease subtype of EOD. This chronic vigilance poses major consequences to the caregiver's wellbeing and becomes a major obstacle to their ability to maintain many aspects of their pre-illness life.

In terms of physical watchfulness, caregiving for this EOD population entails the physically monitoring of the care-recipient. The chronic vigilance of the care-recipient is quite strenuous for caregivers. The care-recipient's loss of judgment causes caregivers to be on constant watch.

065-01-34: For my husband, he's getting up in the middle of the night, at 2 o'clock in the morning, thinking that it's time to get up and get dressed. It's wearing on me, because I have to get up at 4:45 and then I worry is he going to get up again? Where is he at? What is he doing? If I move he wakes up, if he hears anything the house he wakes up. It is definitely a struggle. [50-year-old female caregiver]

This situation is physically exhausting to caregivers as it may deprive them of sleep and has them on constant guard. The direct watchfulness also involves supervising the care recipient during many activities of daily living; caregivers may have to continuously observe or supervise care-recipients because they may have lost the ability to carry out tasks independently.

065-01-34: ...[needs] supervision. If you notice he doesn't have any sideburns. He shaved those off. He shaves clear up underneath his eyes. I say, "Honey you don't have to shave up there."

'There's hair there.' So I don't know where, I've never seen it, but he's not going to have any. It's just, all of those things. [50-year-old female caregiver]

Additionally, caregivers must now also prompt and guide care-recipients as they carry out most of their daily tasks.

065-01-07: And I can see her-she'll be doing her makeup and she'll stop like this...and she'll just zone out. And I'll say, "Come on, [wife's name]." "Oh yeah, OK". [67-year-old male caregiver]

Furthermore, chronic vigilance also entails the need of caregivers to plan and anticipate any potential hazards for the care-recipient. It now becomes the caregiver's responsibility to keep them protected and safe.

065-01-06: He's not going to do that. And if he was-if he ever gets to that stage, I'd make sure things were protected. [50-year-old female caregiver]

The caregivers often take over this responsibility because of the care-recipient's may be unable to foresee the consequences of their actions. Hence, the caregiver now has the task of placing and enforcing safeguards or limits on many of the care-recipient's activities to manage the situation.

065-01-14: But he's allowed to take the golf cart up and down [a nearby street], which is, it's a stretch of about 8 miles, but that's all it is, there's no busy streets, there's no way for him to get out onto any of the regular busy streets, and it's basically from one end of the harbor all the way up to [the hotels]. [52-year-old female caregiver]

Chronic vigilance also involves persistent preoccupation of the care-recipient's wellbeing, even when they are away from them. The caregivers are constantly concerned about the safety of care-recipients because their loss of cognition and function makes them vulnerable to impending dangers.

065-01-14: And he will have just walked to the harbor; and not taken his phone with him, and I think, oh my god, did he walk down to the beach? Did he fall? He's never gotten lost or not remembered how to get home, or that kind of stuff. [52-year-old female caregiver]

This is similar to the concept of "estar pendiente" described by Mendez-Luck (Mendez-Luck et al., 2009), where preoccupation surpasses from only when they are physically with the care-

recipient to a persistent worriedness even when they are not around them. Caregivers feel they must be available for the care-recipient at all times; they feel uneasy when they are not around them. The uncertainty of the situation leads caregivers to be on a constant status of alertness or hyper-vigilance. The caregivers are usually expressing concern for the well-being of care-recipients.

065-01-06: But I just need to monitor, just for my benefit, to make sure that there is nothing going on. That's the only thing I do, is just monitor. [50-year-old female caregiver]

In addition, they not only constantly worry about the care-recipient's wellbeing, but they also feel guilty when they are not around them. Hence, caregivers have little respite from their caregiver role.

065-01-07: I feel very guilty, even though she's quite comfortable and quite self-sufficient during the day. I worry about her in the evening. [67-year-old male caregiver]

This chronic vigilance is reinforced by the care-recipient's increased demand of the caregiver's time as the impairment becomes more prevalent. Care-recipients are often unable to function without the presence or supervision of the caregiver, forcing caregivers to limit many of their activities and accommodate the increased needs of the care-recipient. There is an emotional co-dependency from the care-recipient adding to the caregiver's increased sense of responsibility, reinforcing the urge to maintain chronic vigilance by the caregivers.

065-02-39: She's fine for a night. Overnight is challenging, even if I line up rides for my son. I was out of town for 2 weeks, starting on Feb 21 and came back March 2. I had one show up north and had like 18 hours in town in between before I left to the other side of the country. By the time I get back it was affecting her mood, she was getting depressed. Because I [the caregiver] stopped walking she stopped exercising. So I don't know, 2 or 3 days maximum is what I can count on, without it affecting her. [53-year-old male caregiver]

The caregiver feels responsible for the care-recipient's overall well-being and the need for them to feel supported.

065-02-45: Yeah. I think that...I think she just needs that reassurance that I will be there. You know... [65-year-old male caregiver]

As the care-recipient becomes more impaired, the intensity of vigilance may increase until they are no longer able to care for them.

065-02-39: I'm no longer able to leave her alone for any great period of time. [53-year-old male caregiver]

Hence, chronic vigilance beyond being a major burden and stressor for caregivers may also serve as a catalyst for institutionalizing the care recipient. The increase degree of chronic vigilance may be unsustainable long-term and eventually caregivers seek external resources to attain respite.

Household Tasks

The EOD caregivers tend to also assume the pre-illness tasks of the care-recipients, mainly to maintain a functional household. These are caregiver illness-related tasks because they are new tasks resulting from the care-recipient's functional decline, a symptom of the dementia. Caregivers find it necessary to assume these tasks to maintain some sense normalcy for their family as well as for themselves. Additionally, there may be no other feasible options because these tasks are essential household duties and the care-recipient may be too impaired to complete them. For example, cooking and the fiscal management of the home—if not something caregivers managed before the illness—becomes added responsibilities for the caregiver.

065-01-42: My wife can't put together a meal, if she's going to do pasta. I'll do pasta and chicken and maybe some tomatoes, but she can't. She'll burn something. She can't do eggs and toast and bacon without messing up. So I do all the cooking, but I did most of the cooking since I retired, and I've had to take over the finances. [74-year-old male caregiver]

Driving is another major household task in EOD that caregivers must assume.

Commonly, care-recipients lose driving permissions once diagnosed with a dementia; providers are mandated to report dementia diagnosis to the Department of Motor Vehicles. Hence, due to the illness the caregiver becomes the main source of transportation for the household.

065-01-06: Having to fill in for him as far as now that he can't drive right now, he had his license

suspended, so I'm having to make sure he gets places or kind of help him out filling in his time of the day. [50-year-old female caregiver]

For the caregivers, the uptake of these new household tasks is not optional; they are expected to do these tasks because they are made responsible for the care-recipient. They may also feel guilty if they resist taking on the care needs of the care-recipient.

065-01-14: The primary care doctor called me and he said, "I can't tell you what to do, but if you divorce your husband he's just going to decline and probably end up hurting himself, so if you can go back to whatever made you guys last this long..." So we sat with the primary care doctor, he explained a little bit about this disorder, and I said, "If you're willing to get help, then you can come home." And he knew enough then that he was in trouble. [52-year-old female caregiver]

Care-recipient's Employment

Additionally, caregivers may have to perform some of the care-recipient's pre-illness work-related responsibilities—tasks which may not be within the area of expertise of the caregiver.

065-01-42: She goofed up a lot of people's tax returns, a lot. Fortunately, she was working for somebody and they were insured. She screwed up ours pretty good too, so I have a friend that we've had for years doing it now. I'm not a tax person, but I've got them all together this year, so we'll do that. [74-year-old male caregiver]

This is particularly true in situations where care-recipients have their own businesses and where the main source income for the household is that of the care-recipient. However, this may be only sustainable for a short time during the early-phase of the illness trajectory when the care-recipient is still able to do some of the work. Hence, depending on the complexity of the task, caregivers must either carry out the task themselves or find outside help to maintain the care-recipient's work situation.

Interpersonal

The assistance caregivers provide includes helping care-recipients with their social interactions with others. Socially, they mediate social interactions because the care-recipient may no longer have the language, cognitive, or social skills to properly convey their thoughts or

carryout interpersonal exchanges with others. For example, they find themselves having to speak on behalf of the care-recipient.

065-01-06: Well, hmm. I have to help him out explaining what he's trying to get across verbally to people. [50-year-old female caregiver]

Furthermore, when assuming the added illness-related tasks, they carry them out with a care-recipient who may be resistant to getting help for fear of losing their independence. The caregivers must often negotiate or discuss the tasks with the care-recipient before they can proceed. Thus, these added tasks also entail an emotional burden due to an argumentative care-recipient.

065-01-34: For him to do anything in the kitchen, he wants to help. The burner was on, he stuck his arm over it, and singed all the hair off of his arm. I said, "you can't do that, the burner was on, didn't you see that?" He's like, 'oh no, I didn't see that.' It's adjusting to all of the – even though there are day-to-day things, you have to adjust to all of that as well. Just all those things. [50-year-old female caregiver]

The accumulation of these new tasks may become taxing for caregivers. Routine workloads often double as the illness progresses.

065-01-07: She's up to bed. I have to do the dishes. I have to do my own laundry now. She still does her own laundry. [67-year-old male caregiver]

Non-Caregiving-Related Tasks

Non-caregiving-related tasks are all other tasks that influence caregiving and are not connected directly with the illness. These are a milieu of personal life-related issues that caregivers bring with them during the process of caregiving. In this EOD sample, the predominant non-caregiving-related tasks or issues are related to employment, parenting, and other competing family responsibilities. These are tasks that are normative for people within this caregiver's life-stage categories; however, the tasks are off-time for typical dementia caregivers. Other off-time life stage issues will be discussed furthered in Chapter 4, "Life-course and Off-time Caregiving Issues."

Parenting Issues

The parenting situation is a unique challenge of EOD caregiving. In the late-onset scenario, the adult-child is typically the primary caregiver for the affected individual—over 50 percent of caregivers are the adult-children (Alzheimer's Association, 2017). This is not the case in EOD caregiving; active parenting is one of the non-caregiving-related tasks for caregivers at this life stage. Caregivers are actively caring for young children and young adults who dependent on them. The onset of the illness changes the parenting challenges caregivers confront. The disease itself disturbs their child's emotional wellbeing while most, if not all, of the parenting obligations shift to the caregiver.

Abruptly, EOD caregivers go from co-parenting to becoming a “single parent.” The caregivers lose their co-parenting expectations; they no longer expect the parenting and household situation they anticipated to share with their spouse. Although the care-recipient may still be living at home, they are no longer capable of assisting their children with routine parental tasks.

065-01-34: I feel like I've been a single parent for 3 years, because he's not able to make decisions. [42-year-old female caregiver]

Parenting demands are too complex for the impaired spouse to carry out. Caring for children entails complex cognitive and executive tasks that are beyond care-recipient's capability.

065-01-14: You know, helping the girls through school, and financial aid, and providing paperwork, and all of that now is my responsibility. [52-year-old female caregiver]

Parenting is a particularly demanding situation for EOD caregivers because they must assume the full parenting role without spousal support and with an added caregiver workload.

065-02-39: That's a little bit difficult, other than just having to parent a 12-year-old without the full help of a partner. It's difficult. [53-year-old male caregiver]

Furthermore, the care-recipient's parenting attempts are often not helpful. Although the

care-recipient's impairment constrains their ability to properly address parenting challenges, they may still partake in parental decisions that their children readily obey. Their children see them as the parent they were before the illness with the same parental authority. The care-recipients' parenting attempts are often ineffective and may undermine household rules and the caregiver's parenting authority.

065-01-34: Can I have a birthday party? Can I have my friends come over? The house rule has always been, we parents have to be in the home when other people's children are there, because we're responsible. The girls know this. They would call him, "Dad is it ok if so-and-so comes over?" 'Yeah, they can come over and spend the night.' And I would come home and I'm like, "Where's your dad?" 'He's not here.' "So why do you have your friends over?" 'Dad said it was ok.' Things like that would start to happen. -- [42-year-old female caregiver]

Caregivers find that parenting brings additional challenges. The home situation as a whole is more stressful for EOD caregivers because they must factor in their children's needs along with the extensive number of caregiving illness-related and non-caregiving-related tasks.

065-02-01: It's more tense when the kids are around. [56-year-old female caregiver]

Additionally, parenting demands also change due to the presence of the illness and caregiving. The onset of the dementia, the added caregiving tasks, and the associated adjustments in the household may result in psychologically and behaviorally changes affecting their kids. Also, those with more than one child may have a different set of challenges with each child.

065-01-14 You know, one is from Venus and one is from Mars. [My eldest is] very intellectual and she's very much into the kind of clinical side of it. [My older daughter] and I have just a very different relationship than I do with [my younger daughter]. It's more, it's a warmer relationship is maybe an easier way to explain it. [52-year-old female caregiver]

Their children's emotional reactions vary from denial and anger to embarrassment. Children of a parent afflicted with EOD experience the illness in their own way and may undergo their own grief process. Some of the kids have a tough time accepting the situation and opt to avoid talking about or acknowledging their parent's dementia condition. Parenting is difficult for EOD caregivers who have little control of the situation but still want to provide an emotionally stable

home to their kids.

065-02-01: Daughter wants to “fix” him and is having a hard time accepting any limitations that he has—wants him to “pay more attention” and “try harder.” Stresses him out. Worried about “surpassing her parents.” Son “in denial.” Changes subject. Does activities with dad. Doesn’t want to acknowledge illness. [56-year-old female] caregiver]

Their kids may also express anger and resentment towards the situation, the caregiver, and even the care-recipient. The source of the resentment may be different depending on the age of the child and the stage within the illness trajectory. The caregiver is continuously addressing these feelings to alleviate the emotional turmoil the illness brings to their children.

065-01-14: And I made my amends to [my youngest daughter], I told her I was sorry, it’s been explained to [her] that even if we had known then, the outcome would not have been any different, but she holds resentment that somehow, she wasn’t heard, and yet she was right. [52-year-old female caregiver]

The symptoms of the disease also make the children feel embarrassed of their afflicted parent and their new dementia household. For example, in bvFTD, the patient may exhibit abnormal behavioral symptoms the kids find embarrassing. This is distressing to the children because they are vulnerable and susceptible to what their peers may think of them.

065-01-34: So it has definitely – the girls are struggling with, what’s really wrong with my dad? He would go to the football games, they’re cheerleaders, and he would go to their football games, and stand on the bleachers and act like he’s cheering like them. They’d be like, “mom, he’s totally embarrassing us.” [50-year-old female caregiver]

Additionally, the interactions between the children and a disinhibited care-recipient are challenging, particularly with bvFTD. It is difficult for the children to understand that the actions of their parent are symptoms of the dementia, particularly when behaviors are socially inappropriate and disturbing. This continually creates conflicts and quarrels between the ill parent and the child. The caregiver is often asked to arbitrate these interactions, which they describe as being similar to those between siblings.

065-01-14: So [my youngest daughter] is coming around in her own time, but it’s still very hard. Like, she was there the other day, and he farted, and he didn’t say anything, and [my youngest

daughter] was like, “Mom this is not ok.” “So tell him it’s not ok.” And she’s like, “Dad.” And he’s like, “Oh sorry, excuse me.” That just exacerbates her. [52-year-old female caregiver]

Overall, the parenting situation combined with spousal caregiving is strenuous for caregivers because they continuously face competing, complex demands from individuals who are the most important people in their lives and whom are equally in need of them.

065-01-34: It’s so hard because he gets so mad when I take care of the other girls. Now since he can’t be alone, and I have to work, it’s hell. It’s so hard. My kids, I still need to take care of them, and be there for them. We have our youngest daughter; she’s a special needs child. So I have a lot of doctor’s appointments I have to go to with her. He just doesn’t care. [42-year-old female caregiver]

Caregivers and Employment

Caregiver employment-related issues are especially relevant for EOD caregivers who are within what is considered a normative employment life stage. These young caregivers struggle with their own employment related-issues at the same time as they are providing care to their spouse afflicted with EOD. Compared to their co-workers, these employed EOD caregivers are managing a work situation compounded with other substantial burdens and demands.

065-02-19: So given that I have a more than a full-time job. [50-year-old female caregiver]

Hence, alterations to their employment status, in response to caregiving competing demands, are unavoidable for EOD caregivers.

065-02-45: She didn’t tell me so you know I have to correlate with the doctors and try to remind her, get her going. So, I had to take off work yesterday to get her to the dentist in the morning and take her to another doctor in the afternoon. So, I’m gonna be retired in another month and a half so I have more time to do that and it won’t be a problem. [65-year-old male caregiver]

The work situation along with the disease-related tasks may often become overwhelming for caregivers. Caregivers may need to make employment modifications; they either reduce or completely terminate their employment activities.

065-02-01: Yes—not working now—I’m missing it, but don’t know how I can work full-time and not be available. [56-year-old female caregiver]

However, for many other caregivers altering their employment situation may not be a

viable option because they may now be required to meet the financial needs of the household. Caregivers may become the main financial providers of the household due to the loss of the care-recipient's employment—another consequence of the illness. The financial factors impacting caregivers are described in more detail in Chapter 4, “Life-course and Off-time Caregiving Issues.”

065-01-34: I used to work just to make my car payment or something. The rest of it was to take care of the kids or something like that. Now it's to the point where I have to provide for the family. So, I have to work. [50-year-old female caregiver]

Furthermore, the financial needs may increase and caregivers may need to work even longer hours than before the illness.

065-01-34: I have gone from – I would work – I have to be at my job at 6:30 in the morning and I used to be able to be off work by 2:30. But since all of these changes, luckily my employer knows that I need to get every hour, so I go from 6:30 in the morning, to 5:30 or 6:30 at night. So I do that every day for 4 to 5 days. [50-year-old female caregiver]

Those caregivers that maintain and may even increase their employment must also readjust their household situation to take care of the caregiving illness-related tasks. These caregivers may rely on assistance from paid caregivers to maintain their employment situation. However, getting outside assistance may not be sustainable for caregivers because it poses an added financial burden.

065-01-14: I have a companion that comes into the house. He started out actually as the dog sitter and has kind of morphed into this buddy to [my husband] and they get along great. Or, I would have had to quit my job. [52-year-old female caregiver]

Another way they manage employment while caregiving is to change their work situation. Some can work from home to provide the needed “chronic vigilance.”

065-02-39: Because for the last year I've been working from home—it's been more than a year that I've generally been working from home, but we're on top of each other, all day and all night. [53-year-old male caregiver]

However, working from home is not easy for them because they are not able to concentrate due

to continuous disruptions from the care-recipient. To sustain working from home, caregivers try to set boundaries or obtain home assistance.

065-01-14: It's hard because I do so much work from home, it's getting him to understand that in the morning, until 1 o'clock, that whatever he wants to do is fine, whether it's riding his bike, or taking a walk on the beach, or watching TV, but he's got to leave me alone until one o'clock. [52-year-old male caregiver]

Furthermore, maintaining their employment may help caregivers cope with their caregiving situation. Work may be a positive distraction for EOD caregivers. Some of the caregivers who maintain their employment report obtaining respite from caregiving during the time they spend at work. At work, the caregivers feel that they get a break from the caregiving stressors and have the opportunity to engage in rewarding social interactions.

065-01-34: My out is going to work, but then I'm doing so much at work, that it's just work. The only time that – if I have errands or something, I'll do that on my lunch. I used to be able to, you know, when you have lunch you sit down and have lunch. I don't have that time anymore. I have to put everything that I need to do in a day, in an hour. The social interaction that I get from going to work, and working, it's almost like, I don't know what I would do if I didn't work. [50-year-old female caregiver]

They also find work as an opportunity for intellectual stimulation. However, although they may find work to be rewarding, the rewards are often challenged by the competing burdens and demands of their life.

065-02-19: I try to use my brain. And the way I think of it is, fighting my way out of the paper bag. But you know it's hard between family responsibilities and work responsibilities. [50-year old female caregiver]

However, the employment situation may not be feasible at later stages of caregiving when the care-recipient's needs are greater. Hence, the care recipient's dementia-related impairment might eventually result in caregivers losing or quitting their job because they are not able to perform their work duties. Alternatively, they may decide to institutionalize the care-recipient to sustain their employment. This is especially the case if the financial viability of the household is dependent on the caregivers' employment.

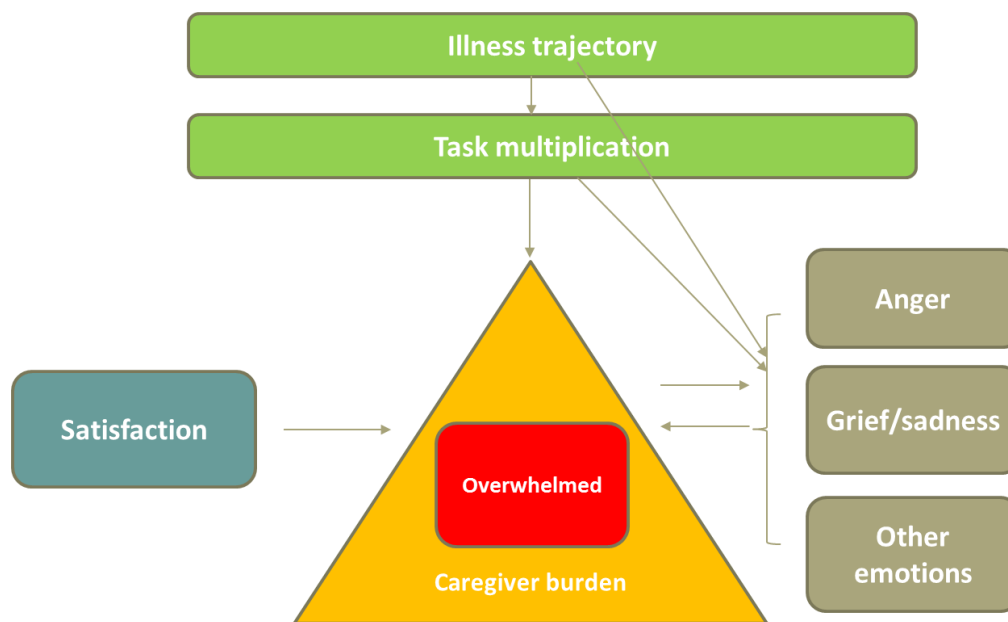
Caregiver's Emotional Response to Caregiving

The overall load described by these caregivers elicits an emotional response that will add to their existing normative emotional status. In this EOD caregiver sample, there is a range of emotions present. The dementia subtype, EOAD compared to FTD, influences the emotional reactions in EOD. Although, the emotions reported are predominately disadvantageous for caregivers, there are also certain aspects of caregiving that they find positive and rewarding.

The emotional status of caregivers fluctuates greatly during the caregiving and illness trajectory. The caregivers' feelings are due, not only to their normative, non-caregiver related life situation, but also by the level of burden resulting from caregiving tasks, their own positive or negative perception of the tasks, and the sadness or grief associated with the disease and caregiving situation (see Figure 4).

065-02-19: He's got his emotional reaction, I've got my emotional reaction, and I've got to try to step out and manage the whole deal. Solve the problem, solve his emotion, manage my own emotions, keep it under control and try to keep going. [50-year old female caregiver]

Figure 4: EOD Caregiving Emotional Response



At the onset of dementia, caregivers are immediately afflicted with an increased burden in their lives due to the multiplication of tasks. The burden is continual throughout the caregiving cycle and will vary in intensity, depending on the illness trajectory. However, the presence of caregiver burden alone does not fully explain the distress experienced by caregivers. It is the combination of the caregiving burden within the context of other life demands that determines how caregivers are affected. Caregivers are concurrently experiencing an array of other non-caregiving life factors (i.e., employment and parenting) that also influence their emotional status. Additionally, understanding the caregiving burden in the context of other life stressors may explain the variability in emotional status seen across caregivers. Although caregivers may experience the same caregiver challenges, these may be embedded within distinct life burdens and assets and support coping capacity. Hence understanding the interaction between these two may help assess the overall caregiver emotional status.

Furthermore, caregiving burden, although present for all caregivers, maybe more manageable for some individuals than others and may depend on the stage of their caregiver trajectory. The moment all these factors exceeds the caregiver's coping capacity, they may find their caregiving situation to be unmanageable or overwhelming. It is within this framework that the results of this study are presented.

Caregiver Burden

The main emotional outcome in EOD caregiving is burden and distress, which is consistent with the emotions reported in the caregiver literature (Pinquart & Sorensen, 2003; Vitaliano et al., 1991). Caregiver burden has been widely studied and firmly established as a hazard for dementia caregivers. However, there are differences in what triggers caregiver burden within the different dementias; within the EODs the behavioral/emotional symptoms, seen often

in bvFTD, versus the cognitive changes in EOAD, may contribute differently to the strain and stress experienced by these EOD caregivers.

Specifically, caregiver burden refers to the strain and stress that results from aiding a frail or ill person with illness-related tasks. In dementia, the level of caregiving burden increases with the progression of the illness trajectory; as the illness progresses, the care-recipient's needs increase until eventually they become completely dependent on their spousal caregiver. The burden experienced by this EOD caregiver population is composed of an amalgamation of the following factors; an increased overall load described by number of illness-related and non-caregiving-related tasks, a lack of coping resources such as decreased personal time, and lack of positive caregiving or reciprocity from the care-recipient. Additionally, life course factors, discussed in Chapter 4, "Life-course and off-time Caregiving Issues," contribute to the burden experienced by EOD caregivers.

Increased Load

The EOD caregiver often becomes the sole provider of their spouse's disease related-needs and assumes responsibility for all household-related issues as described above in the task multiplication process. Caregivers are aware of how extensive of a burden they are now carrying. The load added to their lives due to caregiving is substantially greater compared to that before the illness. They describe an increased responsible for the majority, if not all, of the household duties as they are gradually shifted away from the care-recipient to them.

065-01-14: So it's like I'm in charge of everything. Absolutely everything. There's nothing I can depend on him for. [52-year-old female caregiver]

The presence of the illness results in a multiplication of tasks that may overwhelm the caregiver. The caregivers are already managing many different responsibilities. They find that these competing demands, along with the caregiving obligations, may be too difficult to manage.

065-01-34: I have to find some place for my husband. My one daughter doesn't start school until later, so I take her at 6 o'clock over to my sister's so that she can put her on the bus, and I have to make sure that somebody's home to pick her up. So it is a juggling act. I get tired. So, you do what you have to... It's hard. [50-year-old female caregiver]

The demands generated from the illness often absorb all if not most of the caregiver's time. This all-embracing load shapes the caregiver's feelings. Although not directly stated in the interviews, the heaviness and weariness of the situation is palpable as they perceive themselves as always having to do or manage something to meet the needs of the household.

065-01-34: I don't know. I don't know, because on the weekends when I'm off, I'm cleaning house, doing laundry, trying to get everything done and everything caught up, but then I have doctor's offices to take my youngest to, to take my husband to. I'm just, I'm constantly going. [50-year-old female caregiver]

This continual level of activity is draining and caregivers attain very little respite; they are consumed physically and emotionally by the caregiver-related tasks and the other obligations.

Additionally, even when caregivers are not physically carrying out tasks, caregiving burden may still be present. For example, chronic vigilance, a primary factor described above as continuous hyper-awareness due to the care-recipient's decline, may also affect their emotional well-being. For caregivers, continuously worrying about the care-recipient can be strenuous and debilitating.

065-01-06: It's affected me just, I guess more worries, you know, just a few more worries, just, is he ok? Is he doing what he's supposed to be doing? [50-year-old female caregiver]

Caregiver burden is a chronic condition for EOD caregivers because of the long duration of the illness and the numerous tasks caregivers must undertake. In addition, the situation is difficult for them because often there is little recognition from the care-recipient for their caregiving assistance. Moreover, the care-recipient often criticizes them because they may perceive the caregiver as curtailing their independence.

Caregiver Anger

Another predominate theme in the sample was caregiver anger, which may be associated with the increased burden experienced by these EOD caregivers. The anger described by these caregivers is generally directed towards the care-recipient. The caregivers report anger moments or episodes when they “lose it” with the care-recipients. These anger episodes often occur during their daily interactions with the care-recipient. During these interactions, caregiver expectations of the care-recipient may be discordant from their actual abilities. For example, this caregiver is attempting to use some of the pre-morbid techniques to heighten the care-recipient’s insight as to what they do wrong and to modify their impaired behavior.

065-02-45: She has...I got really mad the other night, I just got my car and took off. And she called me on the phone, and I didn't answer, called me again, and I didn't answer, then she got the message, and she says, "I'm sorry. I apologize. I shouldn't have done that...call me because I'm worried about you." So now, that's when I called her back. And... she's kind of just calmed down since then maybe, maybe now she really knows that upsets me very much so she will kind of hold her anger down a bit. I'm hoping that's, that's what that would've done and I think so far might, it may have. [65-year-old male caregiver]

Hence, a caregiver may perceive the care-recipient’s lack of performance as unwillingness to carry out task and not as a decline in their ability due to the dementia.

*065-01-14: And yet there are moments that **I'll lose it**, because I've asked him to do something to help me and he's forgotten or just decided he doesn't want to do it, and I know it doesn't do any good, but there are sometimes where I'm like, "You've got to try, you know, I know it's hard for you, but you've got to try." [52-year-old male caregiver]*

Consequently, the perceived lack of motivation or cooperation from the care-recipient frustrates caregivers and this triggers caregiver anger episodes. The anger is a release from the frustration the caregiver may feel when they interact with the care-recipient.

065-02-29: The most frustrating thing is that she will not try to do it, she just walks in and hands me the remote control and says please turn the TV on. She will not, she's at the point where she will not try to do that. And that drives me crazy. If there's one thing that drives me crazy is that she won't try. [55-year-old female caregiver]

There are also disease-specific interactions or caregiver situations that may give rise to

the frustration and eventual anger. In EOAD, the anger comes from frustration of the care-recipient's forgetfulness. The caregivers may need to repeat things multiple times for the care-recipient to understand and perform.

065-02-28: I've noticed that I get shorter with her, in that I'll give her the answer. She'll ask me a question and I'll give her the answer, and we'll carry on a conversation and then she'll turn around and ask me the question. Usually it's about the 2nd or the 3rd time that I get a little short and say, "Listen, I just gave you the answer, now just think. What was it that I said?" And I'll try to coax her into remembering the answer that I gave her. Sometimes she just, it's like we didn't even talk. So I get – like I said, I get short with her. [55-year-old female caregiver]

These interactions with the care-recipient may generate frustrations that add to the caregiver's feelings of anger. For example, it is hard for the caregiver to accept that the care recipient truly lacks the ability to remember things; therefore, they unsuccessfully use coaching strategies to remedy their cognitive issues. When the care-recipient fails to perform even when coached, they may become abrasive with the care-recipient.

065-02-28: Some basic things recently have kind of surprised me. Like she's real finicky about having all the doors locked at night time. Lately she's been saying, well how do I lock the door? 'Well you just turn the knob, you don't remember how to do that?' I'll get kind of smart-mouth with her but at the same time I'm trying to get her to remember stuff that she's done normally in previous days or previous weeks that all of a sudden she's not putting two and two together. So then I'm like, "Come on, now think about it." [55-year-old female caregiver]

The anger episodes are also in response to the care-recipient's unpleasant behaviors commonly experienced with bvFTD. The care-recipient's anger and nastiness may spur caregiver anger. Even though caregivers are aware that the unpleasant behavior may be related to the illness, they may still react to those behaviors. Automatically, a caregiver may respond even though they know the care-recipient may not have the capacity to reason in the same way.

065-01-07: She gets them both out, and I'm sitting in a chair in the family room, and I noticed she has that. And I notice she's going to pour the old in the new. And I said, "Don't do that." And she said, "OK." I said, "Don't do that." "OK." I must have said, "No." and each time, my voice is elevating. "No, no, no..." and (sound effect of her pouring the pills like he told her not to). And that's what makes me angry. [67-year-old male caregiver]

The anger episodes then provoke internal reflection from caregivers. Although the anger

episodes are short-lived, they are out of character for the caregiver and it may be a new development in the relationship with the care-recipient. Caregivers find these outbursts disturbing because they see themselves as unable to control the frustration.

065-01-07: And of course my anger dissipated really quickly, but I do find myself getting angry. And it's just-it's not me-I'm just getting really frustrated. [67-year-old male caregiver]

Hence, the angry feelings towards the care-recipient are often immediately followed by self-criticism. The caregivers describe feeling uncomfortable and even disgusted with themselves because, shortly after they get angry, they realize the care-recipient's actions are a consequence of the illness.

065-01-07: But it was uncomfortable for me. I have a problem with getting angry with her, which really bothers me. I know it's not her fault. But she does stuff that, "Why are you doing that?" And she'll just say, "I don't know." [67-year-old male caregiver]

They then tend to feel guilty about their inability to make this connection and control their anger feelings.

065-01-07: At times I'm still disgusted with myself about getting angry with her, which is totally non-productive and doesn't make any logical sense to get angry with her, because she doesn't know what she's doing. It's not her fault. She's not making me angry on purpose. [67-year-old male caregiver]

Furthermore, they see themselves as ineffective caregivers because they are not able to correct the care-recipient's behaviors or improve their memory issues. The anger episodes may also drive caregivers to question their ability to be good caregivers.

065-01-14: I don't feel like I'm doing a very good job. I feel like I'm not as patient as I should be. And I feel like I need to re-evaluate my expectations. You know, I'm just not ready to give up and say...I'm going to keep reminding him he needs to say "please" and "thank you." I don't like that, I don't like being treated like an indentured servant, if you want something say "please." While I understand it's probably fruitless in the long run, I'm not going to give up. [52-year-old female caregiver]

In sum, caregiver anger stems from the caregiver's inability to recognize their own disconnect with the care-recipient situation; they maintain pre-illness expectations during their

daily interactions with the care-recipient. Cognitively the caregiver understands the effects of the illness; however, in their daily interaction with the care-recipient, at that instant, they often fail to make this connection, which frustrates them and ultimately makes them angry.

Other Caregiver Emotions

Caregivers are not only dealing with feelings of burden and anger due to the primary caregiver stressors. They also experience an array of emotions as they navigate the caregiver trajectory. These feelings are continuously emerging in their daily interaction the care-recipient. This section aims to provide a snapshot of the emotional whirlwind experienced by these EOD caregivers.

From the initiation of caregiving, caregivers express *anxiety* because they anticipate an increasing load as they observe how the illness progresses and the caregiving tasks proliferate. EOD caregivers may anxiously perceive a future filled with added burdens and distress.

065-01-14: ...but it's like, "Oh my god what is it next?" [52-year-old female caregiver]

Furthermore, they find that providing care to their spouse is challenging. These feelings are intensified by the changes in character and mood of the care-recipient, which results in *feelings of frustration* by the caregiver. The frustration is fueled by the resistance to get help from the care-recipient, which adds more burdens to the strain they may be already experiencing from the caregiver tasks.

065-02-45: We just went to Carmel for a wedding for four days and she was [in] one of her not so good mood. I want to go out and have fun with everybody else but I can't because I have to be with her and if she says "Oh no, go." And then if I go, then I'm thinking about her in the room just laying there so I'm not having very much fun either. But and that's that happens a lot. Doing things like that. [65-year-old male caregiver]

Hence, caregivers *feel trapped* in this stressful caregiver situation. They feel trapped because of the care-recipient's increased dependency on them and the inability to carry out their personal needs and aspirations.

065-02-29: *[I] come home for lunch every day just to see what he needs. And I'm noticing too that as I'm trying to go, he's always thinking about stuff that I need to help him with. So my job is getting longer. I can kind of see where he wants me to be around a little bit more.*

The care-recipient starts to rely on the caregiver for most of their needs—even simple tasks. The workload of caregivers increases substantially due to the accumulation of these simple tasks and burdens. Moreover, caregivers may be unable to shift these obligations to others, even for short periods of time. They are often unable to utilize outside assistance—primarily because the care-recipient resists help from anybody that is not the caregiver. This limits the opportunities for caregivers to obtain some respite and freedom.

065-02-19: *Another friend invites him out, but [my husband] is somewhat reluctant to go out without me, which really creates more strain on me. 'Cause I would like a little – I would like him to do something without me. Not, you know, not permanently, but... [50 year-old female caregiver]*

Furthermore, doing so much for their spouse curtails their ability to fulfill their own needs and aspirations. The lack of personal time adds to the caregiver's frustration and sense of entrapment.

065-01-34: *So it's frustrating, but it's like, I can't leave home. I can't take him with me. I don't know what to do. I don't know where to take him. So, it's hard. [50-year-old female caregiver][50-year-old female caregiver]*

The sense of entrapment is reinforced by the caregiver's chronic vigilance as described above. Being constantly on guard during caregiving, beyond being burdensome, limits the caregiver's freedom. This hyper-vigilance not only affects the caregiver's psychological well-being but also adds to their feelings of entrapment.

This inability to be away from the care-recipient keeps caregivers from carrying out their own projects and aspirations. This lack of freedom may not only contribute to the caregiver's feelings of burden but also their ability to sustain the caregiving situation itself.

065-02-19: *But it's hard, and frustrating, and overwhelming to think about long-term projects that need to get done. Goals. Even simple things that don't need very much time, I have no time. So even putting in a long-term disability insurance claim, you know something I need to sit down and do. And then I get physically and emotionally exhausted. It's the hardest thing on the face of*

the earth. [50-year old female caregiver]

Caregivers also get very little reward from caregivers. They express *not feeling appreciated* because the care-recipient may lack the ability to show reciprocity due to the dementia. The care-recipient's impairment may keep them from appreciating or even acknowledging what the caregiver does for them.

065-01-14: Then there are times that it's so frustrating and there's so little reciprocation that I think, "Would I have been better off divorced?" And then I feel guilty thinking that. So that's kind of my struggle. [52-year-old female caregiver]

This lack of appreciation may lead caregivers to question why they are sustaining the caregiving situation or why they even maintain the relationship with their spouse. At the same time, having those negative thoughts towards their spouse, whom they are aware has a dementia, makes them feel guilty. The caregivers may be undergoing an array of negative feelings that go beyond the emotional burden of the caregiving tasks. The lack of appreciation is felt more among those providing care for a spouse with bvFTD. These care-recipients have decreased empathy, which inhibits their ability to be aware of the burden caregivers may be experiencing.

065-01-47: I could be gone for eight, nine hours, and she won't bother. I mean if she's--If I know she's going for a walk and she isn't back in two hours, I'm going--"Something's going on. Something's happened to her." I'm a little concerned. She doesn't seem to be too concerned about if I ever come home. You know? I mean, if I didn't show up that night, she might go, "Hey. Where is that dope?" But...she just...for all she knows, I could be lying face down in the sidewalk...but...[63 year-old male caregiver]

Overwhelmed Caregiving

The emotional, physical, and time demands of caregiving become a great concern the moment the situation is too overwhelming for caregivers. The increased caregiving needs due to the multiplication of tasks as well as the associated emotional load may take a toll on caregivers. They find themselves unable to handle or manage their caregiver situation.

065-02-19: And then I get physically and emotionally exhausted. It's the hardest thing on the face of the earth. [50-year-old female caregiver]

These caregivers may become “overwhelmed” with the combination of responsibilities that have been thrust on them. This refers to the moment the caregiver realizes they are no longer able to sustain their own life-related demands as well as the demands generated by their spouse’s dementia. The EOD caregivers may find the needs associated with the EOD exceed their ability to manage their current life. Since this study purposely recruited caregivers who were actively caring for the care-recipient, none of the caregivers were considered “overwhelmed” caregivers. They were all actively carrying out their caregiver role. However, caregivers described situations that potentially lead them to feel overwhelmed.

These overwhelming feelings arise from genuine physical exhaustion resulting from the excessive demands placed on these EOD caregivers. EOD caregiving may entail an overpowering amount of work for some caregivers.

065-02-19: So you know, I stay up ‘til midnight, I get up at six. I could work all night, I could work 24 hours a day. It wouldn’t matter. I still couldn’t get it all done. It’s that overwhelming. [50-year-old female caregiver]

Caregivers are concurrently managing both the illness-related and non-caregiving-related tasks to keep their households running. They are aware that managing multiple caregiving responsibilities, such as providing care for an older parent and child in addition to their spouse while they still work and manage the household, is just too difficult for them to sustain long-term. This is especially true for those caregivers who report a lack of support.

065-02-19: I have a commute, which is a two-hour commute. Then there is the keeping up with [my husband] and with mom. Trying to move forward and make progress around the house, and basically, it’s my responsibility now to look after the property without any help or backup or anybody to rely on, and it’s difficult. [50-Year old female caregiver]

Furthermore, the physical demands are compounded by their own emotional load as well as the emotional status of the care-recipient.

065-02-19: He’s got his emotional reaction, I’ve got my emotional reaction, and I’ve got to try to step out and manage the whole deal. Solve the problem, solve his emotion, manage my own

emotions, keep it under control and try to keep going. [50-Year old female caregiver]

The combination of dealing with their emotions, confronting their own life situations, while physically dealing with the demands of caregiving may push them to a point where things are too much for them to handle.

065-02-29: I just had enough kind of feeling. [55-year-old female caregiver]

Although overwhelmed caregivers were not interviewed for the study, an overwhelmed model was presented. This model proposes that there is a gradation of overall burden and coping that culminates at the proposed “overwhelmed” stage, a stage that may be damaging to the caregiver’s well-being and unsupportive of meeting care-recipient needs. This model can help explain what drives caregivers to make decisions to institutionalize, obtain in-home help, or seek psychological support.

Positive Caregiving

Although the caregiver trajectory is composed for the most part of negative components, caregivers do report some positive rewards associated with caregiving. In this caregiver sample, some caregivers stated that they obtained satisfaction or gained emotional rewards while providing care to their spouse.

065-01-06: So I've internally gained knowledge about people that do have...no matter if it's cerebral palsy, to everybody's different. Every individual is different, and that the person that you see talking and walking with somebody may be a person that has a problem, you know. ... I've gained a lot more compassion for those that--I go out of my way to say hi, or to talk to a mom with a child that is not all there, no matter what type of disorder. So it's been a good thing in one hand. It's been a sad thing on the other hand, that it's happening, but for the most part, I see good coming from it, you know. And hopefully that will be in the future, that people will understand a little bit more so, and understand what I've gained from it. [50-year-old female caregiver]

One of the key categories composing the positive caregiving theme in EOD refers to the opportunity of “spending time” with the care-recipient. This is a change for the care recipient who—before the illness—spent less time with their family and spouse.

065-02-01: *He worked a lot before, so it's nice having him around and more available. [56-year-old female caregiver]*

Although this can be bittersweet for the caregiver because the more time they spend with the care-recipient the more aware they become of the gradual decline and eventual loss of their spouse. However, being aware of the imminent loss also allows the opportunity to better appreciate the moments they have with their spouse.

065-02-19: *The hardest thing is loss. You were saying, it's hard for [my husband] 'cause he's aware of it, and it's like, we're going through this together, and every day, it's so painful. I'm glad that we have time together, and we still have fun, but I can't logically depend on him. It just isn't there. [50-year-old female caregiver]*

They find that as they provide care, they may have occasional moments of joy with the care-recipient. Often these moments are based on activities the care-recipient enjoys and is able to handle.

065-02-45: *Maybe it's going out to dinner, going to a show together, she likes that a lot. You know, going to church together. She likes walking together. I don't do that all the time, but I do them on occasion. And she like's you know, going out to dinner with people and... she enjoys it. So, we get some friends that we've been trying to do this once a week and during the week, go out to dinner. They are happy doing that too. They want to do it. So...that's been helpful. [65-year-old male caregiver]*

The relationship between the caregiver and the care-recipient usually stems from an existing loving relationship established prior to the illness. The caregiver freely and spontaneously shared the loving feelings they had for the care-recipient.

065-01-47: *And I don't want her to feel bad, you know? Or make her feel any worse. I mean...we get along fine. We have our disagreements, but we haven't...I'm with her, 24/7...and the whole time we've been married I just go to work and then come home, because I just want to be with her. And that's the way it's always been with us. I just. I have no desire to do anything else but to be with her. And, she'll still come up and hug me, and when we go to bed she always holds my hand, and...I just...[63-year-old male caregiver]*

There are occasions during the illness period where caregivers see this caring relationship as continuing to be enriched by the care-recipient. The-care recipient may express his affection for the caregiver. They may show the affection by verbalizing their feelings.

065-01-14: And yet, he will still tell me that he loves me, he will still say thank you, he will still apologize if something has come out that kind of made me lose it. [52-year-old male caregiver]

They may also show affection by doing simple acts to please the caregiver. These may be only simple household tasks but they provide satisfaction to the caregiver.

065-02-29: Well he's home. In the morning he's home too. Normally he would be gone by the time I had to get going to work he would be gone. He does, he makes my oatmeal every morning and my cup of coffee. He tries so hard to please, be nice and tries to do stuff. He loves to vacuum, like hours at a time. He helps me do stuff around the house. [55-year-old female caregiver]

They may develop meaningful transforming personal qualities and techniques during the caregiving experience. They sharpen their resilience skills by learning to take control of the situation.

065-01-38: I came up with an acronym. I actually told [the nurse practitioner] too, I did copyright it [laughs] UEC, which means, understand, engage, and communicate. So, I'm still working on, I didn't finish the understand, I'm still working on the engage portion, and I'm still working on the communication program. [70-year-old male caregiver]

They may develop positive coping qualities that benefit their caregiving situation. They gained the skills to have more patience and be more empathetic with the care-recipient. The patience is fueled by a better understanding or knowledge of the illness. They also learn to have more patience by becoming more empathetic; they learn to relate better with the care-recipient by accepting or acknowledging the illness and its associated symptoms.

065-01-07: My patience has increased tremendously. My understanding of what's wrong with her has increased tremendously. And my compassion for her has gotten a lot better. [67-year-old male caregiver]

Chapter Summary

This chapter demonstrates the complexity of the EOD caregiver course. EOD spousal caregiving is compounded and intertwined with difficult tasks and an array of emotions. The caregiving tasks for these EOD spousal caregivers entail atypical issues compared to those seen in the caregiving of late-onset dementia. These caregivers are dealing with mid-life issues, (i.e., employment, parenting) in addition to dementia caregiving-specific demands. The illness-related

and non-caregiving-related tasks involve all domains of the caregiver's life: the household, the workplace, and the social sphere. Hence, the illness generates new and transforms existing caregiving tasks in these domains. These tasks are time consuming and physically and emotionally taxing for caregivers.

These caregivers are undoubtedly burdened; however, the source of the burden is dependent on the subtype—bvFTD or EOAD. The illness-related tasks in bvFTD are shaped mainly by the social, emotional, and behavioral disturbances of the care-recipient; these same disturbances transform the existing non-caregiving-related tasks. For EOAD caregivers, it is primarily the decline in cognition that affects both the illness-related and non-caregiving-related tasks.

Moreover, these tasks often elicit burden and a tumultuous array of other emotions. The caregiver's emotional status is altered with feelings of anger, anxiety, frustration, entrapment, and the lack of appreciation. They encounter these emotions in their routine daily interaction with the care recipient. Additionally, they may encounter positive caregiving components. The positive caregiving factors may buffer the effects of the caregiving burden and distress. The balance of these factors aids in maintaining a functional, although burdened, caregiver: it keeps them from reaching an overwhelmed status.

Lastly, the caregiver situation is embedded within the lives of caregivers, which are composed of distinct contextual factors specific to their stage of midlife. The novel insight provided by the major themes of this study may point to modifiable factors and tasks that, if addressed, may provide relief to the caregiving situation and improve caregiver well-being. Ultimately, this information may also improve the quality of life of the care-recipient.

Chapter 6: “Off-time” Life-course Caregiving Issues

What makes caregiving an “off-time” event?

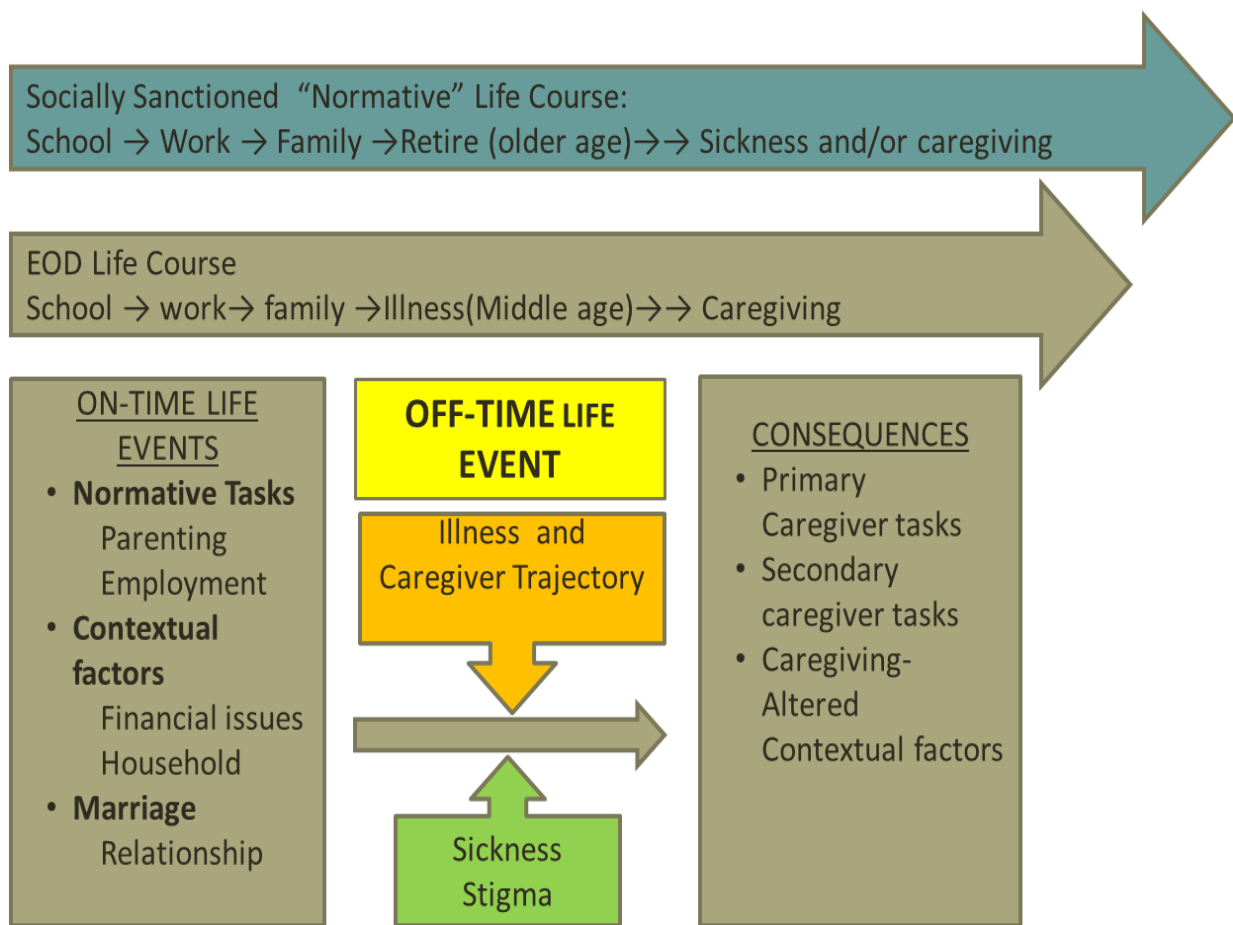
Because of the patient’s “early-age- onset” status, early-onset-dementia (EOD) caregivers are characterized as off-time caregivers whose life conditions are distinct from what is typically expected of a dementia caregiver. These EOD spousal caregivers, in the absence of the illness, would normally be working, child rearing, and experiencing routine marital exchanges. If they were caregivers, it would be for an older parent, not their spouse. The EOAD caregivers in the parent sample were younger (60.0 ± 7.9) than 65 years and most were caregiving for a spouse (79.2%). All were within the “adulthood” and pre-retirement life stage—a period typically defined by age—in this instance people in their 50’s (Elder, 1975; Settersten & Hagestad, 1996; Settersten & Hägestad, 1996). Within this specific life stage, caregivers project normative life-stage expectations and responsibilities, often called life-stage factors. These life-stage factors refer to both the contextual factors influencing the caregiver and the non-caregiving-related tasks presented in Chapter 3, “The Caregiver Trajectory.” These life stage factors were the central focus of these caregivers before the EOD caregiving appearance. This chapter describes emerging off-time categories that define the contextual factors experienced by these EOD caregivers.

The life-course defined contextual factors and tasks are typical of those who are the same ages as the EOD caregivers—employment, parenting, family/marital household responsibilities, and financial issues. As individuals traverse life, they have different roles, often shaped by their age, and which correspond to a socially sanctioned life-stage. Typically, they carry out specific “life-stage appropriate” responsibilities, which they perform jointly with their spouse.

However, the onset of the illness and consequently the EOD caregiving alters these middle-age spouses' life-stage sanctioned tasks and contextual factors. They adopt a caregiver role, which takes them "off-course" from their probable life stage (figure 5). The presence of the dementia in their spouse is atypical within their current life stage. Hence, individuals do not anticipate a possible dementia situation to occur until a future, elder life stage.

065-01-07: It just can't be dementia. That happens to really old people." [67-year-old male caregiver]

Figure 5. Off-time Caregiving Diagram



Thus, EOD caregivers find themselves having to provide dementia caregiving to a spouse at an off-time in their expected life course. This is an unplanned and an unusual life event for most EOD spouse caregivers.

065-01-14: I haven't really read too much of people in my age bracket, they tend to be older, but they were also misdiagnosed for years as bipolar or really more mental illness than FTD. [52-year-old female caregiver]

Sickness Stigma

People around them also endorse these caregivers' situation as being off-time; most people think that an individual with an EOD and the associated caregiving are unusual situations. Thus, caregiving for someone with an EOD has inherited prejudgments from others because most people associate dementia as occurring only to older people.

065-01-14: I get a lot of people that are like, "Oh well my grandmother had Alzheimer's." And it's like, "yeah you're right and she was 80 years old, she wasn't 58 or 59." [52-year-old female caregiver]

Furthermore, these EOD caregivers may feel socially unsupported or misunderstood because of their atypical circumstance. Beyond feeling unsupported, EOD caregivers find they constantly need to speak-out to increase awareness of EODs. They must repeatedly explain to others that dementia and caregiving can occur at a young age.

065-01-14: I wish that in the social media, I wish that it was more known, I wish that people didn't think dementia is something old people get. The way that I've explained it to people is that dementia is very much a word like cancer, and there's many different kinds of dementia and they come in all sorts of shapes and sizes, and they affect people differently depending on what they are, and I just wish that someone more high profile had it, and then it would be not so much like a deer in headlights when you tell someone. [52-year-old female caregiver]

Moreover, EOD caregivers themselves may sustain this bias towards older age. They are undergoing an internal struggle to understand their off-time caregiver situation. Their inner struggle is complex because they are also dealing with grief issues, described in more detailed in chapter 6, "Caregiver Grief in Early-onset Dementia."

Consequences of being Off-time from a Normative Life-course

This off-course condition has consequences in almost all aspects of the caregivers' lives. The onset of EOD caregiving derailed the EOD caregivers' socially expected life-stage tasks and

factors. Specifically, in this sample, the demands of EOD caregiving created situations that resulted in changes in their marital (i.e., marital relationship and household roles and responsibilities) and financial situation. The additional major consequences of off-time caregiving are the key non-caregiving-related tasks of employment and parenting described in chapter 3, “The Caregiver Trajectory.”

Changes in Marital Situation

Hence, the caregivers’ marital situation prematurely changed to what one might anticipate experiencing in old age. Among the respondents in this study, the presence of the EOD altered the marital relationship that most caregivers shared with their dementia-afflicted spouse. The caregiving off-time condition imposed major marital consequences. Caregivers felt that, due to the illness, they lost their marriage and a spouse, as described in Chapter 6, “Caregiver Grief in Early-onset Dementia.” This loss refers to overall changes in the home context, which includes the supportive, comforting, and protective environment they enjoyed previously. It also refers to changes to their role within the marriage at an unexpected time in their lives.

Beyond the grief associated with the loss of the spouse, caregivers no longer find the ease and comfort they used to have in their marital relationship. Their home lost its sense of familiarity and safety; it may no longer be the place they envision or the marriage they signed up for.

065-01-42: You connect with people because you have a familiarity and you’ve shared some likes. I understand music pretty well because I played for years. My wife understands art pretty well so we used to enjoy the musical things which I could explain, which could be either the philharmonic, or just a rock concert, or whatever. And then we’d go to the art museum where she would – so we just kind of shared that. [61-year-old female caregiver]

The disease has major consequences on the couple’s emotional relationship. The patient’s illness and symptoms contribute to a household that may become less nurturing for the caregiver.

The household may now lack the intimate emotional support they shared with their spouse prior to the illness.

065-01-42: Practically everything we do now instead of being close to each other, we're further apart. [74-year-old male caregiver]

This is especially true for those caring for someone with a bvFTD, an EOD subtype where individuals have lost their ability to emote. Hence, bvFTD patients may not be able to reciprocate emotionally in the marital relationship compared to before the illness.

065-01-34: I don't think so. I do not think so at all. He'll say, "Oh, I love you, you're the best thing that's ever happened to me," and things like that at least 50 times a day. And I'm like ok, but then by the end of the day, 'You already told me, it's ok, you don't have to tell me.' [42-year-old female caregiver]

The caregiver's emotional expectations are lost with the onset of the dementia and this affects how they may perceived their home. Specifically, their marital situation changed significantly from what they knew before the illness, altering the home they once felt connected to. Their household was a critical component of the caregivers' life context; it would have normally provided a safe haven to caregivers. Now, it is a home devoid of its hope and dreams.

065-01-47: I don't know, maybe we were stupid, I don't know, but we were just, we were content. Being with each other. That's all we wanted...and, like I said, I thought when we would retire it would be...a lot more fun than...you know, her staring off into space, you know. [63-year-old male caregiver]

Changes in Household Tasks

The changes in their marital situation drives caregivers to reassess their expectations of what the care-recipients can now actually contribute to the household. Caregivers abruptly become singly responsibly for the household needs—a household that now also entails caring for a spouse with dementia. Ultimately, they are required to take on most of the household responsibilities along with assuming most illness-related and non-caregiving-related tasks. For caregivers, the onset of the EOD entails an overall alteration of their home situation or home

context.

065-02-19: But there seems like an endless list of maintenance and things to be done, and what's really hard is that I can't, I can't turn to [my husband] in the way that I could in the past. As an equal. As a partner. And what's really hard is the loss of that. That's the hardest thing. [50-year-old female caregiver]

Additionally, most take on the new caregiving needs of their spouse who may eventually become completely dependent on them, like another child.

065-01-34: I don't feel like I have a marriage anymore. I have another child... I mean, I feel guilty saying that, but I just I don't see it. There isn't. It's no longer a companionship, it's just, I have another child and that's what I have. [42-year-old female caregiver]

Thus, the household situation for EOD caregivers is an off-course alteration in their expected life. In this stage of their life, they anticipated to have a spouse who was their partner and who would help them carry out the “on-time” household obligations and provide companionship. The onset of the EOD displaced the caregivers’ home situation off their expected life course, forcing them to readjust so that they can meet the challenges posed by EOD caregiving.

065-02-29: I'd rather have been taken care of whatever. So yeah, it's changed things. [55-year-old female caregiver]

Financial Issues

Individuals often base their financial decisions and plans according to their life stage, in this case a midlife stage. Their immediate areas of financial concern include dependent children, household expenses, future finances, and employment and retirement benefits. These EOD caregivers have children and young adults that depended on them financially. Additionally, at this midlife stage, parenting expenses may include major schooling expenses such as college tuition. Additionally, prior to the onset of illness, most EOD caregivers were financially planning and saving for their future retirement.

065-01-14: Well just kind of people in my situation. Midlife, and you think financially you're going to be ok, because you've worked hard and we chose to send our kids to a catholic high school, and we've chosen to help our kids pay for college. [52-year-old female caregiver]

EOD caregivers may also be at a stage where they make long-term financial decisions. At midlife, they may have attained employment stability and have a limited number of years to save for retirement. However, at onset of caregiving, they may discontinue their programmed retirement savings due the loss of income and/or increased expenses resulting from the dementia and associated caregiving demands.

065-02-01: Financially, our future is much less secure. Concerned about getting a retirement that's going to provide enough that I don't have to go back to work full-time. [56-year-old female caregiver]

Therefore, the EOD caregiver's financial priorities shift to accommodate the unexpected dementia caregiving situation. Due to their off-time caregiving condition, they face major financial consequences that alter the course of their life-stage and result in financial distress. Although financial distress can occur at any life-stage, it is unforeseen for most people in their midlife to experience financial distress due to dementia caregiving. Furthermore, due to their off-time condition, the financial challenges may be different for EOD caregivers than for late-onset caregivers.

The financial factors varied among EOD caregivers, depending on their pre-caregiving financial status. The financial effects of EOD caregiving range from reports of their situation being financially catastrophic to unperturbed. For some of these EOD caregivers, the off-time caregiving results in a fiscal crisis for their household and it may become a critical factor as they provide caregiving.

065-01-34: I'm to the point where I don't know if we are going to have to file bankruptcy, or what I'm going to do? You can't claim – you can't get unemployment when you have this, so I'm trying to get social security and have him with his disability and all that. It takes time. So it is definitely a financial struggle. My parents have helped out, my sister has helped out. His mom and dad, they don't feel it's their responsibility. So it's hard. [42-year-old female caregiver]

Another financial concern for caregivers may be their inability to plan for their immediate future. It is difficult for them to plan because of the uncertain nature of the illness.

The dementias in this study are entail a long and progressive situation, with no defined precise timeline for caregivers to predict their future financial needs.

065-01-38: No doctor can give you the important information, which is for example: Should I take out insurance or put her into a home? When is that going to happen, or is it going to happen? Is it going to happen 5 years or 10 years, when I cannot take care of her? Is it silly, I get from the state government, I get these letters prepare from old age, now the answer to am I going to be able to take care of her in 10 years, or is she not going to be around in 10 years or 5 years, or 1 year? You see all of these, the whole rainbow. [70-year-old male caregiver]

Furthermore, the off-time dementia caregiving situation has very distinct financial consequences for EOD caregivers. Most find that they must make decisions they had not planned to make until later in their lives.

065-02-19: Things are ok...we're not financial geniuses. We certainly didn't expect— I didn't expect [my husband] to go out with disability at basically the age of 53. [50-year-old female caregiver]

Reasons for Financial Issue

The principal financial concern comes from the loss of present and future income.

Commonly, both spouses may have contributed financially to the household before the illness.

However, the care-recipient is eventually unable to sustain their employment due to the EOD.

065-01-14: Clearly he'll never be able to even remotely do anything that would allow him to earn any money. [52-year-old female caregiver]

Hence, the loss of income from the care-recipient can have a great impact on the financial household situation. This especially true if they were the primary breadwinners in their household.

065-01-14: So far it's been pretty significant. He has no income, because he was an independent contractor. I don't know how this is going to affect the SSI process. [52-year-old female caregiver]

In some instances, they not only lose a substantial portion of their household income but also the medical benefits that come with employment—services that the caregiver may also be personally benefiting from.

065-02-39: When she was a teacher she was making somewhere in the neighborhood of \$45k a year, and she had full benefits. So subtract \$45k from our family economy and also right when this happened, right when she lost her job I lost a situation. [53-year-old male caregiver]

Hence, caregivers may have to compensate for the loss of these benefits to the household—another unexpected costly expense to deal with once again. These may be an expense much greater than before the illness because they must now purchase individual insurance plans that are more costly.

065-02-39: She has annuities that she built up with 6 years of teaching that disqualifies. So our benefits between my son and myself we're up to \$1000K a month. So, 12K a year, and hers is another 100 a month, so we're around \$13-14k a year, plus copayments, plus procedures and all that stuff. I just paid \$1200 for the excess of my package, for my hospitalization that I went through for diabetes. [53-year-old male caregiver]

Additionally, as explained in Chapter 5, "The Caregiver Trajectory," there may be loss of caregiver income because they may not be able to work due to competing caregiving demands. Dementia caregiving, at an off-time, results in an overall critical decline in income for most households.

However, for some, although the situation may be financially strained, it can be manageable.

065-02-19: So, we're ok, we're not great. He's got disability, social security... [50-year-old female caregiver]

However, due to the lengthy course of the dementia situation, financial stability may not be achievable long-term, even for those with some resources. At some point, these caregivers may find themselves at the brink of economic crisis. Thus, the prospect of financial issues may be a persistent concern even for these EOD caregivers that may be better off economically.

065-02-39: So it's been difficult. We're not a position where we're going to lose anything at this point, but another 5 months off we'll be close to the edge. [53-year-old male caregiver]

Financial Assistance

Furthermore, off-time caregivers and care-recipients may only be able to obtain a portion

of their retirement benefits and public assistance compared to those in a similar situation who are older. Typically, older dementia caregivers have full retirement benefits and easily qualify for public benefits. On the other hand, EOD caregivers and their care-recipients usually have not contributed enough years of employment that would grant them with retirement compensation. Additionally, at their mid-life their benefits are connected with employment status; care-recipients may be able to receive public assistance after diagnosis only if they meet stringent criteria.

065-02-19: And it's about – it combines to be a little less than half of what he used to make when he was working. And basically, I planned on having him work until he was 65 and kind of feather our nest. [56-year-old female caregiver]

Thus, they are often required to navigate the health care and financial assistance system, which typically they would not explore until older age.

065-02-01: Has been really difficult-social security and disability and insurance all very confusing. Feel very ill equipped to deal with those issues. [53-year-old male caregiver]

However, the process to qualify for these typical “old-age” benefits is precarious and laborious.

065-02-52: So I'm on Cobra health coverage until he's six months short of getting Medicare, if nothing changes. Wow. If this disability happens, that would be great. Yeah. Okay. Okay. So right now...So that's been weighing on me big time. I spent a lot of, everyday off that I've had, I've spent on...gathering information, getting online: How should we say this? How can I prove this? You know, what document should I have with me that will make this case work? And then they say sixty percent of them, they turn down their first time anyway so... [61-year-old female caregiver]

Furthermore, they may have to pay out-of-pocket for many of the dementia-related expenses while they wait to qualify for government programs.

New Spending Demands

Their financial worries surpass the typical midlife concerns of paying a mortgage, saving for retirement, or meeting the needs of the household. They are also dealing with the costly caregiving demands associated with the onset of the dementia, which entail substantial out-of-pocket expenses. Many of the respite services such as a home health aide and transportation are

costly. Most of these care-recipients may not have long-term care insurance to cover this cost; typically people purchase long-term care insurance at about 65-years old (Brown et al., 2007).

065-01-08: The thing was- “get a driver for [your husband], to take him everywhere.” Well, the thing is, I did that a few times, and there was a driver, very, very nice man, but it was \$200 for four hours. [73-year-old female caregiver]

The direct financial cost of the dementia itself is a challenge for caregivers and one for which they did not prepare. Their financial situation, which may have been stable prior to the illness, may now be precarious. Furthermore, the financial consequences may have lasting effects on caregivers. They may not be able to recover from the financial losses resulting from caregiving.

065-02-29: Because money wise and stuff like that. I don't know if I'm going to be able to even have a house by the time it's all over. I want to do as much as I can but I don't know. So I'm scared about that. [55-year-old female caregiver]

However, there are also EOD caregivers who do not experience major financial challenges due to dementia caregiving. In this sample, there were EOD caregivers who stated that dementia caregiving does not signify a major alteration to their financial wellbeing. This may be because there are caregivers who are better financial planners and are prepared to resolve unexpected financial events.

065-01-07: I've always planned, financially, to take care of her. So we're well-off, financially. She's gonna be well-off financially. There's no problem with finances. [67-year-old male caregiver]

065-02-28: Well, we were fortunate in that we were both teachers and both had a pension coming to us. If it hadn't had been for that – I mean, we took a 40% paycut, but by moving up there and getting out of here, things are less expensive up there, we don't do as much traveling, gas is less, groceries is probably about the same. [66-year-old male caregiver]

Additionally, not surprisingly, those with greater financial resources do not experience a major financial disruption in their lives due to EOD caregiving.

065-02-45: Financially, no, no...I have a pretty good job. I can work more or work less. I can pretty much do what I want to do with that job. I can go to work or not. That's the way it's set up.

And like I said, I'm gonna retire at the end of September is my last.. last day. And I feel that I can make [more time] \on my retirement. I have money put away, so I think that will be okay. [65-year-old male caregiver]

EOD Caregiving Support Resources

These EOD caregivers' off-time condition puts them at additional disadvantage because they may have limited access to care-recipient and caregiving resources. They find that there is a scarcity of age-appropriate dementia services for both care-recipients and for themselves.

065-02-19: In that most of these programs are designed for, as far as I can tell, for older folks and most of the people in them are 20 years older than [my husband]. And the spouses and the caregivers of the people are retired, and it's a huge strain. . [50-year-old female caregiver]

065-02-29; For him and I would love it if there was a meeting that he could go to. Me and him – you know, and there would be younger people, not real old. [55-year-old female caregiver]

Additionally, many find the typical support services directed at providing caregiver support are ineffective because their EOD caregiving problems are different.

065-02-29: So I went to just one meeting and I didn't really like it. But I kind of thought, I know this is going to do me some good. But it was mostly older people. There was a couple of younger people, but I really felt like I really wish I was with some younger, you know, not the really old ones, because our problems are different. So yeah... I wish there was something like that in my area, I would kind of like to go. [55-year-old female caregiver]

Many also find that existing respite services for care-recipients, such as adult day-care programs, are set-up for the typical Alzheimer disease subtype; these programs are often unprepared to handle those care-recipients with non-memory related dementias.

065-01-42: I never know the myriad – the delusions I think are the biggest, we go to a group and most of the people that are in the group while I'm in the other caregiving group have Alzheimer's, theirs is more of a memory than a behavioral. [74-year-old male caregiver]

Their own predispositions may keep them from seeking existing support groups because many also perceive dementia to be composed of older spouses. Furthermore, they may not perceive typical dementia support groups to be able to deal with their issues, which they see as being different due to their age and life stage.

065-02-28: My vision of being in a support group is sitting around listening to a bunch

of old grannies or grandpas.” [66-year-old male caregiver]

Furthermore, their off-time condition may hamper their capability to use these services. Many services are offered during the workday or when they are fulfilling their parental role.

065-02-19 There are no Saturday programs. It's going to have to happen as the Baby Boom ages, and I just think, there are all these great programs out there, but not for working people. Not for caregivers that work. That's a real frustration for me. [50-year-old female caregiver]

Chapter Summary

This chapter finds the timing of dementia is a key factor when evaluating the caregiving situation in EOD. It recognizes that people have a socially sanctioned life-course. EOD caregivers, who are at a midlife, are already handling multiple challenging and demanding life factors. The “on-time” life events for caregivers may be challenging; however, they are expected and planned. Therefore, encountering a caregiving off-time life event both augments their existing load and disrupts many of other factors in their lives. This is important because it indicates that the major consequence of EOD caregiving may be how it displaces the caregivers’ existing life situation.

The effects of being derailed from their socially-sanctioned life course are multi-layered for off-time EOD caregivers. Principally, since non-caregiving-related tasks and contextual factors in EOD are directed by an individual’s life-course, they are the key factors that delineate a caregiver’s off-time status. The emerging non-caregiving-related tasks categories of parenting and employment, described in Chapter 3, are unique to EOD caregiving; these categories may be the central activities at this midlife stage. Hence, the presence of the illness changes the type of employment and parenting challenges they may now confront. Along, with alterations in their midlife activities there are also alterations in key areas of their contextual milieu. For these spousal EOD caregivers, these include major alterations in their household and marital situation

with the overall loss of a spouse or companion. Additionally, beyond experiencing the loss of their home life, they find their lives are compounded with new burdensome caregiving demands. Additionally, their financial situation is altered by the illness—the presence of the illness changes financial earning opportunities and increases expenditures. The alterations may also include financial uncertainty for the future.

In addition, caregivers deal with the immediate affects brought by the onset of the illness and the subsequent caregiving. In the off-time condition, the illness and the presence of caregiving pose distinct information and emotional challenges. These caregivers are uninformed, if not perplexed, about dementia occurring at their current life-stage. Hence, the EOD spouses are ill-prepared to deal with the caregiving challenges. Lastly, there are emotional effects because this situation entails an unexpected loss of their dreams and aspirations. An EOD spousal caregiver confronts a unique set of challenges that require an age-appropriate supportive network of resources.

Chapter 7: Caregiving as a Trajectory

The aim of this chapter is to propose descriptive profiles of EOD caregivers at distinct stages of the disease process. Although this is a cross-sectional study and there were no caregiver follow-up visits, there is evidence that caregiving may have a demarcated trajectory. Caregiving is not a static but rather a dynamic process that responds to the changes and demands of the illness, the caregiver's mastery of the situation, and their ability to adjust to their off-time life condition.

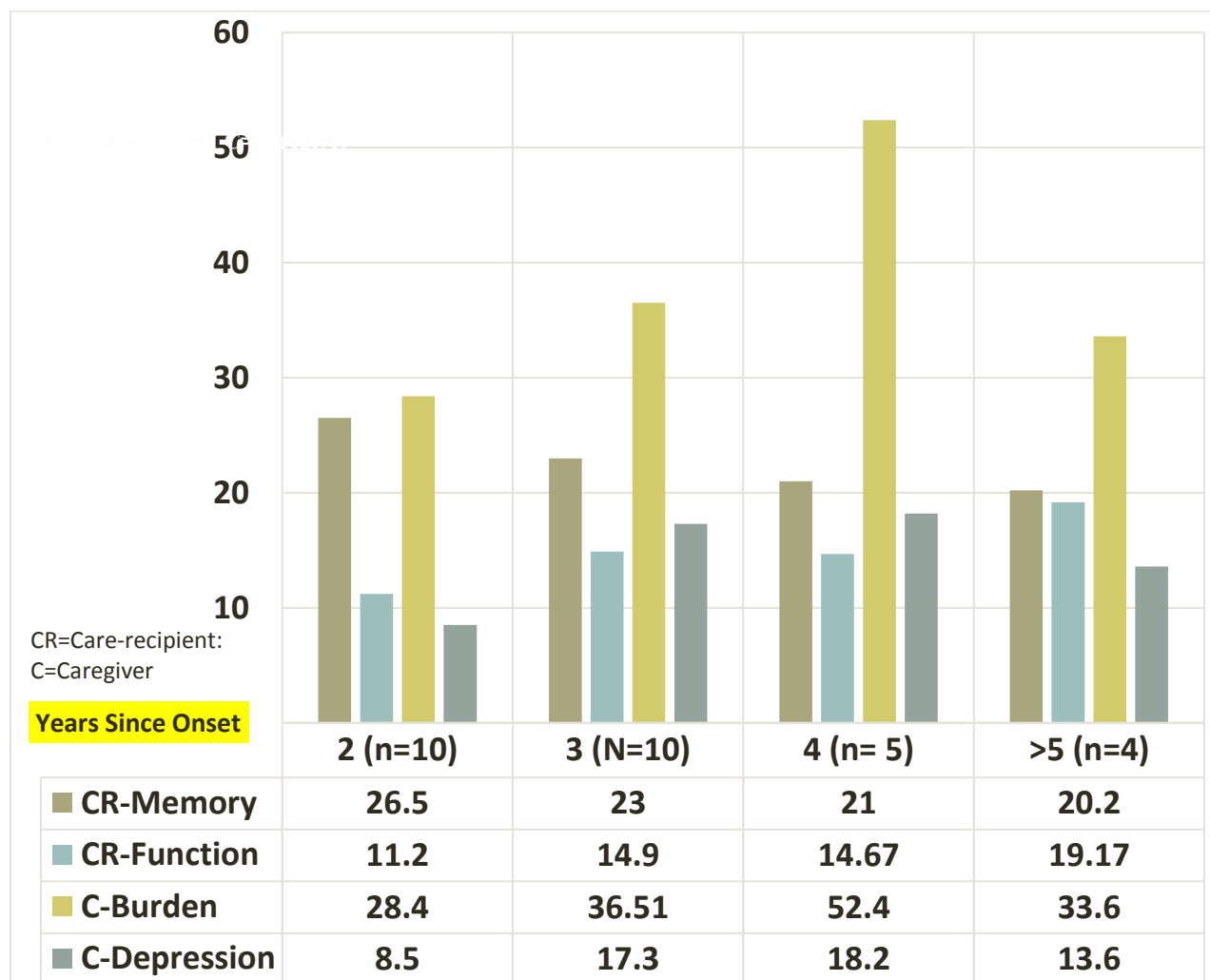
To explore caregiving at various stages of the illness course, the data in this study were stratified by the number of years caregivers provided care to their dementia spouse. The number of years since the care-recipient's onset of the disease were used to identify the length of caregiving; these yielded four groupings (see Table 5). The early stage includes those that had been caregiving for 2 years or less; middle stage includes those caring for 3-4 years, and at the advanced stage, those caregiving 5 years or more. Note that given the course of a typical illness, most EOD sufferers survive 9.1 years (Seltzer et al., 1983) and they are typically diagnosed in year 3 from disease onset (Snowden et al., 2011). Furthermore, most will eventually reach five years; however, disease progression may be too advanced for the care-recipients to participate in dementia studies.

The stages were characterized using quantitative measures of cognitive and functional status of the care-recipient and self-reported measures of burden and depression for caregivers. These quantitative measures were used mainly to describe the sample.

Of the quantitative measures, the care-recipient, as expected, showed decline of cognitive and functional abilities at these various stages (Table 5). Specifically, the care-recipients showed decline in cognition at each successive stage as measured by the mean Mini-Mental State

Examination (MMSE)—the smaller the score the greater the decline. Similarly, there is an increase in functional impairment at each stage, with an increase mean score at each stage on the Functional Assessment Questionnaire (FAQ)—the higher the score the greater the disability. The caregivers showed increased caregiver burden on the Zarit Burden Inventory (ZBI) for groups in years 2-4 and a decrease at group ≥ 5 —the higher the score the more burdensome the caregiving situation. Additionally, the caregivers showed a similar increase in depression based on the Center for Epidemiological Studies-Depression (CESD)—the higher the score the greater level of depression.

Table 5: Disease Onset (yrs.) vs CR-Memory, CR-Function and C-Burden and C-Depression



Hence, over time, as impairment increased so did caregiver burden and depression. The care-recipients appeared to have greater caregiving needs due to increased impairment resulting from the disease progression. Additionally, EOD caregivers seemed to respond to the care-recipients' decline with corresponding changes in caregiving burden and depression (Table 5). Caregivers, at the initial 4 years of the disease, have consistently greater burden and depression each year while the care recipient had lower cognitive and function abilities. Those providing care for someone in the advance years (>5 years) of the illness, compared to prior stages, had less burden and depression in light of greater functional and cognitive impairment of the care-recipients (Table 5). However, this is not a longitudinal study and we can only describe how these caregivers are at those year points. Overall, there may be varied caregiver load and the emotional wellbeing at different times during the caregiving cycle.

Subsamples of corresponding qualitative interviews were analyzed at each stage. Specifically, the interviews were employed to further profile the caregiving situation at the different stages of the disease. The interviews provided details of the caregiving situation to understand how it may be changing at various stages. The aim was to understand what factors contributed to the changes in caregiver burden and emotional distress shown in the quantitative scales. At each stage, caregivers and care-recipients face challenging situations; however, the nature of challenges and stressors may be distinct at each stage.

Stage 1: - New Life Situation (Early Caregiving Stage)

This initial stage of caregiving occurs within 2 years of disease onset. Caregivers are just settling into their new situation and are starting to assume new challenges.

065-01-45: I just have to kind of change and kind of figure things out I think I'm starting to help. Starting to get that figured out. Not completely but it's a little bit better than it was. [65-year-old male caregiver]

Understanding the New Situation

Due to the newness of the diagnosis, these EOD caregivers struggle to understand the dementia as it is occurring in their spouse. At this stage, they may gather information on the illness and symptoms. Additionally, they may start to reconcile the changes they have observed in the care-recipient with what is known about the illness.

065-01-38: Now the diagnosis was done only in July, when we had the other neurologist involved in this. So before that it was just, what's wrong with her, that sort of thing. So they have to overcome, 'what's wrong with her,' to 'that's what it is.' We have to accept it. She's a strange person right, so that still – I'm working on. [70-year-old male caregiver]

065-02-68: But I have no idea what it's going to be, because I don't know what it is. So yeah, that I wish. I don't think I'm scared for her. I'm scared for me in a lot of ways. [52-year-old female caregiver]

Some of the respondents described their attempts to understand the affects this illness may have in their existing life. They wanted to understand so that they can interact better with the care-recipient. Additionally, a better understanding of the situation may help them re-adjust their expectations to align with their new EOD reality.

065-01-65: The only fear I have, right now – I mean, I know that this is a progressive thing – I don't want to say the house burning down, but at the same time, the house burning down. Because I don't know what my husband is capable of. I don't know what he's not. I don't know how his mind is working right now. I'm kind of still in the dark about all of that. What does he really know and what does he not really know? [female caregiver]

Emotionally, at this stage, the caregivers may be at the initial phase of their grief course described in Chapter 6, “Caregiver Grief in Early-onset Dementia.” This may be the first instance they might confront the distress and sadness associated with their spouse’s illness.

065-02-68: You're probably the only person I've talked to about it this way, with a handkerchief out. No, there's not really anybody to talk to about it. I talked to my brother briefly that it's not going to get much better. I'm planning to talk to the kids about some of it – I just haven't really put together all my thoughts on it. [61-year-old male caregiver]

High Functioning Care-Recipient

Furthermore, the care-recipient, at this stage, may still be high functioning in many other

aspects of their lives. They may still be working, driving, and carrying out many of their routine activities. However, even if they are still able to carry out many of these tasks, there is a notable change in their ability; caregivers are commonly attentive to these changes. Some of the care-recipients are aware of their decline and of the caregivers' watchfulness; this often elicits displays of frustration and anger from them. This is particularly true in EOAD where the care-recipient may have greater insight or awareness of their dementia-related decline. Hence, they may struggle to maintain their independence and resist the caregiver's attempts to provide aid.

065-01-34: For one thing they still have their sense of autonomy, and they know "I have been able to do this in the past." That's part of the thing, because if I leave him with the girls and they say, 'dad you can't do that,' or 'dad come sit down,' or 'dad do this.'" He'll say, 'I'm a 45-year-old grown man, I can make my own choices.' And they look at him like, 'we know that dad, but you're going to hurt yourself.' [42-year-old female caregiver]

The care-recipient's resistance to their situation creates friction with the caregiver. At this stage, many caregivers were trying to re-define their relationship with the care-recipient but also identify techniques to manage the EOD situation.

065-02-45: The main thing I think she doesn't like me reminding me her of things and I have to because she won't do them and I guess she feels that I'm very repetitive I keep telling her things and like I said if I don't do it then she's not gonna get that. She has to be at her doctor's appointment at a certain time and I said "Look, you gotta be there at a certain time." And she just not be ready and I see getting oh I don't know if I see it maybe the third time and the she just...everything blows up. And I just have to walk away. [65-year-old male caregiver]

Initial Readjustment

This readjustment is also to accommodate many of the other changes that arise due to the dementia situation. This stage may entail, for caregivers, alterations in multiple life spheres. Their spousal relationship, home structure, work, finances, and parenting situation may be altered to due to EOD caregiver demands; EOD alterations are described in more detail in Chapter 4, "Off-time" Life-course Issues in EOD Caregiving."

065-01-34: It's adjusting to all of the – even though there are day to day things, you have to adjust to all of that as well. Just all those things." [42-year-old female caregiver]

Primarily, some caregivers may start to identify new ways to interact with their spouse. They learn that they must readjust their interaction with the care-recipient to accommodate their decline in cognition, function, and behavior. For example, in response to memory decline some report that they must remind the patient more frequently to get them to complete tasks.

065-02-45 Yeah. I'm writing notes and then I will write her notes and I will remind her but now I won't remind her as much as I write the notes. So just not telling her kind of helps out. It...I just have to kind of change and kind of figure things out. [65-year-old male caregiver]

The number of simultaneous tasks caregivers must perform also characterizes this stage. For one, caregivers continue to sustain many of their pre-illness obligations while absorbing the new caregiver tasks. Typically, at this stage of their life course as discussed in chapter 6, “Off-time Life-course Issues in EOD Caregiving,” caregivers are juggling many different components such as employment and children. These obligations persist with the same intensity at this initial stage of caregiving. Furthermore, they add on the new EOD caregiving obligations to this challenging pile of obligations. Thus, at this early stage, caregivers may be finding ways to manage all competing obligations— not many were removing existing demands.

065-01-34: I don't know. I don't know, because on the weekends when I'm off, I'm cleaning house, doing laundry, trying to get everything done and everything caught up, but then I have doctor's offices to take my youngest to, to take my husband to. I'm just, I'm constantly going. [42-year-old female caregiver]

065-01-65: I'd say it's right now, very overwhelming. It's like a tsunami. I have a lot of things that I know that I have to do on a legal basis, and a preparation basis, and on a daily basis. I think I'm having trouble focusing, meaning I have to breathe, relax, focus, see what I need to do first, kind of thing. But at the same time, it's at least, everybody handles stress differently. [Female caregiver of unknown age]

However, at this initial stage caregivers do begin to recognize and accept that they may need to make changes in their life situation to accommodate the demands of the dementia. They were “planning” and not necessarily making major changes in their lives.

065-02-45: I think it will be better for her that I'm home more often and I know it won't be better for me, but it will be better for her. And that's pretty much it. [65-year-old male caregiver]

Additionally, at this initial stage, caregivers may be ill prepared to handle the added caregiving demands; they often lack the knowledge necessary to care for individuals with failing memories, disturbing behaviors, and less social and emotional cognition. Many EOD caregivers are not using external caregiver or dementia informational and support resources or services. They may be just beginning to explore what is available that may help them in the future.

065-01-65: Well, since this is all new, I recently went to an IHSS meeting for In-house Supported Services. What that requires and how you can get help. Either someone coming in or you're paying, or whatever. There are some things that I actually need to do first before I can apply for that. One of them is MediCal. My sister has MediCal, my husband does not. So I'm going to try to apply to MediCal for him to see if he can qualify for that. Then apply for IHSS and see if someone can come in, at least for part of the time. [female caregiver of unknown age]

Furthermore, most are not getting assistance during this time. Caregivers may not know how to access available social support or caregiver or dementia resources that may help them manage their caregiving position. Additionally, some caregivers are reluctant to accept formal services and may not feel comfortable relying on others for support. Thus, even if services are available, some caregivers may be reluctant to use them. In this sample, it is unclear how open to help caregivers may be at this early stage. No emerging concepts supported either resistance or openness to both formal services and support from others. However, there was an indication that that most were not using many outside resources at this early stage.

This early stage is also the time when the caregiver may disclose the illness to others around them. This may raise tensions with the care-recipients because they may want to keep the situation private from others; this may be difficult because often others notice changes in them—particularly obvious changes in behavior.

065-02-45: They [friends] had known so she was missing appointments and missing dinner appointments with them and so I had to call up few of them and you know, this is a problem, we always thought something was going on but we just didn't know what it was. And then a couple of them called me and asked me. And then that's, she doesn't want anybody to know. She doesn't think anybody knows. And she says don't tell anybody I have a problem like this. Please, don't do that. I have to do it. [65-year-old male caregiver]

Hence, the disclosure could bring caregivers either social support or isolation; as such, comfort or greater stress. For one, family and friends may find the diagnosis difficult to accept and may either distance themselves or create additional conflict for the caregivers. Others may provide caregivers and care-recipients assistance with the care-recipient's needs and emotional support for them.

065-01-34: My family has been pretty good, because my family lives here. They've noticed big changes and things like that, and they just try to overlook it, you know what I mean? His mom and dad, in the beginning they thought that he was just making it all up. I tried to tell them that there was something seriously wrong, and nobody believed me. They didn't believe that he had any problems. [42-year-old female caregiver]

Lastly, at this early stage caregivers are still able to enjoy many pleasurable aspects of their relationship with the care-recipient. The care-recipient is at the mild stages of the illness; therefore, the illness does not disrupt the relationship the couple had before the illness—they still enjoy spending time together. Many more at this stage, compared to later stages, reported continuing with the same pleasurable activities such as going to parties, movies, spending time with family, and traveling. They felt that caregiving was satisfying because they were spending and enjoying quality time with care-recipient.

065-02-45: On occasionally we do. Not all the time. But you know right now she's in a real good mood. We are enjoying each other. [65-year-old male caregiver]

In sum, the demands of early-stage caregiving may not be as extensive or demanding as those experienced in advanced stages; however, early-stage caregivers are less equipped to deal with the demands and emotional distress associated with illness.

Stage 2: Adjustment (Intermediate Caregiving Stage)

The adjustment stage is a much more defined situation for caregivers. Caregivers may have a greater understanding of the EOD and its consequences. At this stage, some of the caregivers displayed greater insight into the illness—they had been caregiving for a longer time.

065-01-07: I've gained a lot of knowledge about what is going wrong with her. My patience has increased tremendously. My understanding of what's wrong with her has increased tremendously. And my compassion for her has gotten a lot better. [67-year-old male caregiver]

At this stage, some caregivers may have developed mechanisms and gained greater mastery of the caregiving tasks principally by attaining a better understanding of the illness. They may also have accommodated their lives in response to the demands of the dementia, thereby reducing the uncertainty and gaining more control of their situation. For example, by this stage some caregivers had made changes in their employment and home situation to ease their load. Specifically, some caregivers have either stopped working or reduced their work hours.

However, the caregiver demands may have continued to increase during this “adjustment” stage. Some of the caregivers reported an increase of the care-recipient’s physical, behavioral, and cognitive impairment. In turn, this may have brought more challenges for caregivers. Furthermore, some reported that care-recipients were less capable of contributing to the needs and obligations of the home at this stage. In addition, they may need increasingly and constant direction on how to carry out many activities of daily living.

065-02-30: I sit there now. If there's a deadline, like this morning, I sit there and I can see her as she sits down to do her makeup and she sits down to do her hair. And I can see her-she'll be doing her makeup and she'll stop like this...and she'll just zone out. And I'll say, "Come on, [wife's name]." [48-year-old male caregiver]

On the other hand, at this stage, although the care-recipient’s illness is advancing, caregivers may not need to provide yet hands-on assistance with routine activities of daily life such as dressing and bathing their spouse. Most care-recipients were still able to perform many of their daily personal needs.

Emotionally, there is less internal conflict experienced by the caregiver as they become more accepting of their caregiving situation. Specifically, they may readjust their pre-illness expectations to align to their current caregiving reality. These include expectations of what the

care-recipient is realistically capable of doing, what they themselves can manage, and what they can expect emotionally from the spousal relationship.

Most caregivers may have readjusted their expectations of the care-recipients so that they more accurately reflect their actual functional and cognitive abilities. This may reduce the caregiver's feelings of frustration in their daily interactions with the care-recipient.

065-02-30: Then the other thing I've realized not too long ago is I can't expect my husband to learn from his mistakes for the future. Like if he said he was going to do something and he didn't do it. [48-year-old female caregiver]

Additionally, they may have re-evaluated their marital relationship so that their emotional expectations align more closely to the person they are presently dealing with and not the one before the illness.

65-02-30: My relationship with my husband is...we're having to relearn how to have a meaningful relationship and I've been consciously making notes of things to myself, mental notes. Last Fall I realized that I had to not expect him to remember anything, but that I needed to still tell him what's going on so that he feels included, but I expect him not to remember so that I don't get upset when he asks me three times because he forgot. [48-year-old female caregiver]

Furthermore, many caregivers changed their own behavior to accommodate changes in the care-recipient. Principally, most find they now have to be more patient with the care-recipient. Some report utilizing new such ways of interacting with the care-recipient; they may now reassess the situation and factor-in the illness before responding to their spouse.

65-02-30: So just being patient. Especially if I've worked all day and then having supper, and then after supper trying to talk through what's happening the next day or making plans for Thanksgiving. Are we going to stay here or go up to see my parents? Why do we take half an hour to figure this out? I have it...Ok, just got to be patient. Opportunity to develop the virtue of patience. [48-year-old female caregiver]

They now understand that the patient may lack the capability to correct many of their behaviors. Therefore, caregivers may be more aware that it is up to them to respond to the care-recipients' changes and readjust both the care-recipients' and their own behavior to be effective within new situations.

65-02-30: *I can't try to convey to him what to think about what he might do different in that same situation in the future. Instead, I have to learn from his mistakes. I have to learn that he may say he intends to do something but he may not. So instead of – so I need then, to realize that he generally means to do this, but he might forget. So how do I find a diplomatic way to prompt him or mention, 'are you aware that it's 9 o'clock and I heard you mention that you were going to finish those dishes before you went to bed.' I need to do that. [48-year-old male caregiver]*

The caregiver's improved understanding of their caregiver situation opens their awareness to external resources that may help them with present and future caregiver tasks. For example, they may start to look for external resources such as paid caregiving assistance, supportive institutions, and support groups for themselves. They find this to be challenging because there is a scarcity of resources specific to EOD as discussed in more detail in chapter 3, "The Caregiver Trajectory."

065-01-07: *So as far as resources, that's the only thing...you know, I have a folder called "Caregivers," and when I run across something I'll stick it in a folder for "maybe someday." There's a website called "Alzheimer's Weekly" or something like that I go to that-it's been very helpful. There's a section of it called "Ask Nurse Nancy" or something like that, and some of those questions are helpful, because they do talk about FTD. [67-year-old male caregiver]*

In addition, at this stage, caregivers may start to appraise the emotional consequences of their situation. Some appeared to start to have a better handle of their emotional situation since they have had time to consider and begin to accept their caregiver role. They may have realized that their spouse is no longer able to contribute emotionally as they did before the illness. Hence, during this readjustment stage they explore ways to safeguard their emotional well-being.

65-02-30: *So am I supposed to feel down and scared because he is? Well, no. I want to enjoy my life that I have now as much as possible. So, I can feel like I'm being hard hearted if I feel happy and I know he's terrified. Or if he's at home, I wonder how he is when he's at home alone all day and try to have him not be alone all day, but we get back to that question of how much am I responsible. Legitimately, how much am I responsible for his sense of wellbeing? To some extent I am, and to some extent I'm not. Regardless of how much I am responsible for him, **I must take care of myself.** I must be emotionally independent and have appropriate boundaries. I need to have fun, and I need to have time for myself. [48-year-old female caregiver]*

For those caregivers who have been caregiving for a longer time, the feelings emerging appear to be less raw, which may free them to start dealing with the emotional distress and sadness that

arise from caregiving.

Overall, caregivers experience less uncertainty about their life at the readjustment stage. Primarily, they may be better informed and have started to accept some aspects of the dementia situation—thus changed accordingly to accommodate their new caregiver situation.

Stage 3: Proficiency (Advanced Caregiving)

At this stage of caregiving, there is greater proficiency and mastery due to an even greater number of years of caregiving. The caregiver may have had the opportunity to build the skills to manage most of the caregiver illness-related and non-caregiving-related tasks they confront. Additionally, they may have learned to readjust to the continuous changes exhibited by the care-recipient. However, although not found in this sample, some caregivers may have burned-out with little support to manage the increasing demands of the care-recipient's disability. This is a convenience sample where only caregivers who may be better adjusted agreed to participate.

However, the care-recipient at this stage requires greater assistance due to unavoidable and continual decline. Thus, the care-recipients' changes at this advanced stage may increase burden for caregivers. Caregivers may now be providing their spouse with more hand-on assistance with their daily activities compared to prior stages.

065-02-39: She's really needy. She can't put on clothes by herself. She can't fold laundry. She's spatially challenged because of the actual specific type of – when a piece of clothing comes out inside out from the dryer, she cannot figure out how to turn it inside out. If one leg on a pair of pants is inside out, she cannot turn it inside out to figure out where to put her hand and where to grab to pull it out. When she has the clothes, she can't remember how to fold them at all anymore. Anything that has more than one step of direction is beyond her. [53-year-old male caregiver]

The care-recipient's dementia changes during this period also entail increases in behavioral issues that may be more distressing compared to prior stages.

065-02-28: it's kind of like maybe everything inside of her is maybe spinning out of control and so in order for her to get control of this, whatever it is that's spinning around in her head, that is why she feels this need to be involved in my world. "Are you cleaning up the garage? Are you going to turn the light off? Are you going to close the garage door? Are you going to do this, are you going

to do that? Are you going to bring the tractor in? Are you going to leave it out?" That kind of stuff all the time [that he does], that becomes a source of irritation at times. [66-year-old male caregiver]

Overall, during this mid-to-late stage of caregiving, the care-recipients may start to become more functionally dependent on the caregivers and their behavioral changes may be less manageable.

However, some caregivers receive greater assistance and support during this stage compared to earlier stages. First, caregivers at this stage may be more open to accepting help—many reported using more outside resources. Second, some had established a network of resources that helped them deal with the demands of the illness. Last, some caregivers were less socially isolated and received support and information from others.

065-02-28: I have a friend of mine, down the street who I help him, he helps me when it comes to mechanical, physical, electrical, that kind of stuff. Our chaplain friend has encouraged me to get into a support group, I still don't see the need for that, nor has that been a priority for me. But she feels I should get into it. Then I have the support of her family up there who love to do stuff. We all get together as a family. [66-year-old male caregiver]

At this stage, caregivers may develop multiple coping skills that help them deal with their emotional distress. They may routinely implement these coping mechanisms in their daily activities, particularly in their interactions with the care-recipient. Furthermore, they may have identified key strategies that work for them.

065-02-19: I try to use my brain. And the way I think of it is, fighting my way out of the paper bag. But you know it's hard between, family responsibilities and work responsibilities. So, I do tend to triage. I do tend to take care of whatever's on top. [50-year-old female caregiver]

Furthermore, caregivers may continue to work on mastering these skills.

065-02-28: I've had to become much more patient. I have a long way to go, but I mean, I love her. I love her dearly. [66-year-old male caregiver]

Additionally, at this stage, caregivers may have gained a greater awareness of the consequences of illness; they know, first hand, the unpreventable decline in the caregiver-recipient. Thus, since the changes in their spouse are more notable, they have become more aware of the future consequences of the illness. Although they did not directly express these

concerns in the interview, there are indications that they may contemplate these long-term consequences more frequently. For example, some identified the potential severity of illness and appreciated the fact that their spouse is still not at that stage. Additionally, they may be more consumed with grief-related issues. Other aspects of grief are addressed further in chapter 6, “Caregiver Grief in Early-onset Dementia.”

065-02-28: But she hasn't gotten there yet thankfully. I'm hoping she stays the way... [66-year-old male caregiver]

At this proficiency stage, although the caregiver may have better skills to manage the caregiver situation, the overall degree of impairment of the care-recipient may still be significantly burdensome for the caregiver. Additionally, they may be struggling emotionally with grief as the care-recipient's decline becomes more pronounced.

Stage 4: Normalization (Advanced Caregiving Stage)

At the “normalizing” stage in caregiving, the caregivers expressed less burden and depression. At this stage, caregivers may have incorporated caregiving as a normative component in their lives. Unfortunately, the data for this last stage is not very robust due to exclusionary criteria of the parent study. The parent study, as an exclusionary measure, had a Mini-Mental State Examination (MMSE) cut-off score of 20 (a measure of 23 or less is consider cognitive impaired) (Folstein et al., 2000); this is a measure of the care-recipients' cognitive ability. Hence, this study systematically excluded caregivers who provide care for those at the advanced stages of illness. However, a few patients which had an onset at > 5 years were enrolled, and information can be gained from these few caregiver interviews.

At the normative stage, caregivers have years of experience caring for spouses with an increasing cognitive decline. Since, at this stage, they may have a better understanding of the disease and its consequences, they might not be impacted by the illness in the same way as they

were in the earlier stages. Thus, due to the length of caregiving, independent of disease severity and progression, they may be incorporating dementia caregiving as a normative component in their lives.

Many of the care-recipients at this stage were too impaired to independently carry out many of their routine daily activities. Furthermore, most of the care-recipients' level of need was much greater at this stage. The majority were dependent on the caregiver for most of their needs.

065-01-61: It's going pretty quick. I'm afraid it's going to be sooner than later. I mentioned to you earlier that we had our first accident last weekend. I don't know what's going to happen then. She tends to be pretty private about that stuff. And I'm not sure if she had an accident or not. She could have spilled water; I just don't know. I don't think so. [43-year-old male caregiver]

However, the changes in the patient may not have the same impact on caregiving burden and emotional distress as it may have had early in the process. Furthermore, the patient's illness might not add significant impact to the caregiver because they may already be doing a lot for the care-recipient. Additionally, caregivers at this stage may have gained mastery of caregiving tasks and may be using more external caregiving resources.

Most caregivers seem to be more willing, at this this advanced stage, to place their spouse in a skilled nursing facility because they find caregiving too much to handle. Unlike earlier stages, many are well informed of their choices and prepared to make these changes. However, most find that the financial burden is still a major issue as they consider placement options.

065-01-61: One of my biggest concerns is long-term care. I'm pretty pragmatic, what do we have to do? I'm not working right now, very much. There's not a lot of income coming into the house. Who is going to pay for all of this? Just the basics. [43-year-old male caregiver]

Additionally, the increased impairments of the care-recipient may not affect the caregiver in the same way. At this point, many have already assumed most of the household responsibilities and the care-recipient is mostly dependent on them. The added burden, which may entail a greater intensity of existing tasks, will not proportionally change the caregiver

workload. Nevertheless, a substantial degree of overall burden may still be experienced by these caregivers.

065-02-29 And yeah, I'm just too tired. It's like I don't have the time. I used to have a...group, so about once a month we'd get together. And I quit that this year too. I just had enough kind of feeling. [55-year-old female caregiver]

This later stage, although less explored in this chapter, may provide insightful ideas to better equip EOD caregivers.

Chapter Summary

Overall, it appears the caregiving situation is dissimilar at different times during the caregiving lifespan. The proposed stages model is limited in that it does not provide longitudinal information on the same cohort. However, it does provide evidence that the length of illness may lead to variations of the care-recipient's abilities and needs, which subsequently may alter the caregiving situation. Specifically, in this sample, there were timespan variations for some of the care-recipients. Those who had been dealing with illness the longest had a greater decline in function, behavior, and cognition. This is consistent with the EOD literature where disease progression is a required component in dementia criteria (Mendez, 2006). The caregivers had, for the most part, analogous incremental changes in burden and depression in each year grouping except for the latter years where the group appeared to have decreased burden and depression.

The principal aim of this chapter was to profile the distinct stages of caregiving and to identify and describe the dimensions of the variations at different time points. Hence, in this sample, some caregivers displayed demarked caregiving lifespan variations in the number of competing demands, adjustments to caregiver life, mastery of caregiving tasks, and level of emotional stability.

The caregivers who described dealing with the greater number of competing demands

were those at the initial stage of caregiving, the “new life situation.” Most of these caregivers were absorbing new caregiving tasks while maintained their existing life obligations chiefly unchanged, while those at later stages may have adjusted to decreases the number or intensity of competing life demands. Hence, adjustments were most commonly seen in caregivers at the mid-stage, or “adjustment stage,” where caregivers described substantial life changes to accommodate the caregiver demands. This involved the need for caregivers to readjust their non-caregiving-related tasks and contextual factors.

Mastery was captured by the caregiver’s description of their skill at handling the caregiving situation. The emergence of this category was most notable in those caregivers at the latter stages, principally by those in “proficiency group,” while those at early stages mostly described a need for information on the disease and better skills to interact with the care recipient. Additionally, based on the tone of the caregivers, many in the later years seemed to have greater confidence in their ability to provide caregiving. Caregivers described emotional stability more often at the later stages of caregiving, at the “normalization stage.” Most of these caregivers had less grief-related and burden-related categories, unlike those at the earlier stages where loss and burden were at the forefront emerging concepts. Additionally, the caregivers in the advanced stage group were more willing to address difficult subjects such as long-term care. Additionally, some mentioned distressing care-recipient changes such as incontinence with little emotion and were equipped to accommodate the change. Appraising this advanced group was challenging because this was the least studied group with greater selection bias. Mainly mild cases were selected to participate.

This study is a first attempt at introducing an EOD specific caregiving trajectory that segments caregiving into defined stages. Although other trajectories may have been presented in

the literature, this study included changes in the EOD care-recipient to inform the stages. Thus, robust testing of this caregiver trajectory model is needed. This model could potentially help guide and design stage-appropriate caregiver interventions informed and guided by the disease.

Chapter 8: Caregiver Grief in Early-onset Dementia

Early-onset dementia (EOD) caregivers experience not only burden and strain while caregiving but also feelings of loss and sorrow, identified here as dementia caregiver grief. Grief may be particularly significant among spousal caregivers when dementia occurs early as opposed to later in life because there are greater interrupted expectations for the future.

What is Grief in this EOD Population?

Most caregivers interviewed in the study reported the presence of grief due to caregiving; 90 percent of caregiver interviews contained grief-related quotes. The reported grief emerged spontaneously from the data since formal questions of grief were not included in the original interview guide. In all occurrences, caregivers were asked unrelated questions about caregiving or the illness and they responded with fragments or phrases that displayed grief due to loss. Feelings of grief are salient in EOD caregiving because caregivers continuously confront loss and sorrow as they interact with the care-recipient or carryout caregiving tasks.

The grief experienced during the process of caregiving is known as pre-death grieving since it takes place before the death of the care-recipient. Pre-death grief is different from the typical grief or bereavement experienced after someone dies; it is complex and multi-dimensional. Pre-grief is an "in-between place" people find themselves in when someone is dying (Noyes et al., 2010). It arises in response to the care-recipient's anticipated death and the loss of the relationship they enjoyed before the illness. Additionally, caregivers also grieve the loss of the life they had before the illness, specifically the loss of their personal freedom and the sense of a "normal life." These general concepts of pre-grief in this EOD population are consistent with what the literature describes as grief in the dementia caregiver population (Arruda & Paun, 2016; Chan et al., 2013). However, the factors and situations eliciting pre-grief

in EOD are different compared to other caregiving situations.

Furthermore, caregiver grief is not experienced as a sequential process but as episodic grief events triggered by the progression of the illness. There is no indication from this study that those at the latter stages of caregiving experience greater grief than those at initial or middle stages. This is consistent with the literature, which suggests the caregiver grief trajectory is non-linear (Blandin et al., 2015). This also aligns with the concept of temporality influencing the illness and caregiving experience as described in Chapter 6, “Caregiving as a Trajectory.” Grief triggers will occur concurrently with the illness and caregiver trajectory described in Chapters 4 and 5.

Grief contributes greatly to the caregiver’s emotional status during caregiving. EOD caregivers find themselves in an ambivalent emotional status throughout their caregiver career, a feeling brought about by the uncertainty of the illness and disease course. This same uncertainty influences their grief experience; caregivers may have a difficult time understanding or even recognizing their feelings of loss and sorrow that emerge during caregiving. EODs are relatively rare conditions that have not been well studied and whose disease course is not well established. Hence, caregivers feel uninformed and less in control of their emotional status. The uncertainty faced by EOD caregivers due to the uncommonness of the illnesses is distinct compared to other dementia caregiving situations.

065-01-07: I think what bothered me the most was I always figured that Alzheimer’s was terminal. Your brain eventually forgets how to breathe. But I always assumed frontotemporal was just a mental thing and she would just eventually go away mentally and be put in a home somewhere and be taken care of. But now I’m finding out it is terminal, but anywhere from 5 to 30 years. Well-I’m in the same category. So I don’t know. There’s just so much happening and there’s so much unknown. It’s not like, “she’s got liver cancer, and statistically, if you don’t get a transplant, she’ll die in x amount of months.” It’s not like that. She’s just going to slowly change mentally. [67-year-old male caregiver]

The caregiver’s emotional ambivalence can also be attributed to the fact that the care-

recipient's decline is not visually noticeable, unlike other illnesses with obvious physical changes. This is also true when compared to late-onset-dementia where the care-recipient may appear frail, particularly due to compounded comorbidities associated with age. EOD care-recipients are typically physically healthy with few comorbidities (Mendez & Cummings, 2003). This is especially true at the early phase of the illness. Although the care-recipients have cognitive or behavioral decline they still appear visually unchanged; it is difficult for the caregiver to accept the feelings of grief for the loss someone who appears relatively normal.

065- 01- 14: "I appreciate hearing that, but it is, it's terrible. He's dying. Effectively he's dying, and he's not dying. I don't know how to say it without sounding really morbid, but there are some people that I'm almost kind of envious of whose partners are in the active stages of dying, and they're going to die, and yet my husband, his brain is dying and he's not. And it's a weird predicament because you can't say that publicly. And not have people think you're completely twisted. [52-year-old female caregiver]

Furthermore, caregivers may not consistently obtain the emotional support or understanding from others because the illness is not also easily noticeable.

The grief experienced by this EOD sample had two major emerging categories: anticipatory and concurrent grief. These refer to the two types of grief that may occur during pre-death grief, each may be triggered by distinct caregiver factors. Anticipatory grief included anticipated death of spouse, lost future together, lack of ongoing spousal companionship, and financial uncertainty. Concurrent grief occurred as caregivers grieve real-time dementia-related changes in their spouse, included loss of spouse personhood/personality, loss of marital relationship, and loss of household partnership. Bereavement, which is grief due to death, was not included in this study since all care-recipients were still living at the time of the interview.

Anticipatory Caregiver Grief

In this EOD caregiver sample, grief is experienced principally as caregiver anticipatory grief. At first, with the initial shock of the diagnosis, caregivers experience anticipatory grief as

they become aware of the terminal nature of the disease and the proximal death of their loved one. Caregivers are aware early in the caregiver trajectory that their love one will die because of the illness. The outcome of the illness is discussed at the early stages of the illness, commonly first confronted at time of diagnosis. Hence, the diagnosis initiates pre-death caregiver grief in EOD; the identification of the illness alerts caregivers to the eventual death of the care-recipient.

065-01-14: "...we had already established with a neurologist in [a nearby city] who basically told me it was a death sentence, I mean that's – and then I told you about my other visit with him. And I'm like, 'Well there's got to be something. I'm not comfortable with 'There's nothing we can do.' "There's got to be something we can do' [52-year-old female caregiver]

Anticipatory grief is a process that may last many years for dementia caregivers. Hence, EOD caregivers may not have a well-defined anticipatory grief course with a distinct starting point and demarked stages.

065-02-39: It's not a normal cut and dry Alzheimer's: here's the timeline, get your affairs in order, and say goodbye. [53-year-old male caregiver]

The anticipatory grief reported by the caregivers includes not only on the eventual physical death of that person but also the loss associated with the future they had planned together. This grief due to loss of future prospects is specific to these dementia caregivers managing someone with an “early-onset” condition. They do not perceive this loss of future in the same way as those caring for someone with a “late-onset” dementia. The concept of loss of future in this EOD population refers to the prospect of not “growing old together,” a situation different from the older spouse caregivers who have already experienced the “older life stage” with the care-recipient.

065-02-01: Worried about not growing old together. Worried about him not recognizing me. [56-year-old female caregiver]

EOD caregivers may experience grief due to the loss of plans and prospects of a future life with the care-recipient. Specifically, they grieve the loss of their own future expectations and dreams,

which they perceive to have been stolen by the illness. The loss of future provokes a great deal of uncertainty for caregivers.

065-01-06: The other is what the future holds, you know, but I try not to harp on that too much, unless...it's brought up, or unless maybe a family member, or unless you ask a question like that...then, I think, "wow, what's going to be happening in the future?" but I don't think about it constantly or out of the blue, but when that time comes up I'm kind of, you know, but when I do, it's like...so, that's basically. [50-year-old female caregiver]

Additionally, they lament the loss of those "golden years" they expected to share with the care-recipient. As is commonly planned by most couples, caregivers envision sharing with the care-recipient a less complicated and freer life foreseen at the latter stage of their lives or during retirement. Hence, the EOAD caregivers confront the realization that, due to the illness, their expectations of shared golden years may not materialize as they had planned.

065-01-14: I thought after [my husband's] mom died, which was a long and protracted, uncomfortable situation because she effectively just killed herself I mean, she didn't outwardly kill herself, but she was an alcoholic and she wouldn't accept help and she was unhappy and difficult to deal with. I kind of thought that once she had died this burden had been lifted, and we were going to have this sort of, ride into the sunset life. [52-year-old female caregiver]

Furthermore, the caregivers' present life expectations are also interrupted; they did not plan or expect the existing dementia caregiving situation.

065-01-14: And we're not. And just changing the perspective of what our lives are and that's what I'm struggling with, in that this wasn't how it's supposed to be. [52 year-old female caregiver]

Lastly, there is grief due to the loss of financial stability the caregiver expected to have at the later stages in their lives. Because the financial future of spousal caregivers is linked to that of the care-recipients, they are aware of changes in their future financial prospects, leading caregivers to lament the loss of their future joint financial security.

065-02-19: And it's about – it combines to be a little less than half of what he used to make when he was working. And basically, I planned on having him work until he was 65 and kind of feather our nest. [50-year-old female caregiver]

A great portion of the grief due loss experienced in EOD caregivers may stem from the

condition of being off their typical life-course stage. Many express grief due to loss of sharing future expectations such as retirement or the “golden years.” Typically, spouses at midlife have plans and expectations of the future they will share with their spouse. Instead, these caregivers unexpectedly find themselves having to prepare for the eventual decline and death of their spouse and the loss of their shared life.

Concurrent Caregiver Grief

Caregiver grief is not only due to eventual losses of major life components, but it is also grief due to small routine situations or interactions in the caregivers’ lives. As the illness progresses and the care-recipient declines, EDO caregivers experience concurrent grief.

Concurrent grief is real-time ongoing grief experienced by caregivers as they carry out their caregiver role and as they respond, in real-time, to the changes in the care-recipients’ situation. It is the feelings of loss and sorrow experienced by caregivers due to observable declines in the care-recipients’ cognition and function as well as the changes in their behavior, personality, and the relationship they shared with caregiver. Concurrent grief, unlike anticipatory grief, results from the caregiver’s awareness of loss encountered during daily interactions with the care-recipient; they encounter episodes of decline that highlight the gradual loss of the lives they shared, the person they knew, and the relationship they valued. These gradual and continuous episodes of loss of the care-recipient trigger measured doses of emotional distress.

Caregivers grieve the gradual loss of their love one’s “personhood.” Specifically, this refers to the loss of the care-recipient’s personality, changes in conduct, as well as their impairment in memory and overall function. The loss of personhood in this dementia population is consistent with what is reported in the literature; the illness may destroy many aspects of the personality or life memories that had enriched their marital relationship (Tolhurst et al., 2014).

065-01-14: And just changing the perspective of what our lives are and that's what I'm struggling with, in that this wasn't how it's supposed to be." [52-year-old male caregiver]

Specifically, as the care-recipients' dementia progresses it robs caregivers of the person they knew. This realization triggers continuous episodes of concurrent grief. Caregivers recognize, though daily encounters with the care-recipient, how the person they knew and love slowly fades.

065-02-19: And it's like, 'yeah, I did.' It feels so bad, because I don't have anybody to back me up; for me. Not to just sound like I'm feeling sorry for myself, but it's the loss of that person. [50-year-old female caregiver]

065-01-34: It's really hard for me because I feel like he is completely not the person that I married. He hovers, and he's like on top of you. It's like – it's very hard. Especially because he is completely different than who he used to be. I feel like in a sense, I've been grieving, because he's already gone... it's not fun. [50-year-old female caregiver]

The companionship refers to the loss of emotional and physical intimacy as well as the romantic aspects of their relationship. They feel that they have lost the spousal connection they had prior to the dementia. Their relationship becomes unequal; it is more analogous to the relationship they share with their children. They lost their equal partner within the marital relation.

065-01-34: I mean, I feel guilty saying that, but I just I don't see it. There isn't. It's no longer a companionship, it's just, I have another child and that's what I have. [50-year-old female caregiver]

They may also feel that they no longer have a confidant in their spouse. They lost the key person with whom they used to share their routine and major life occurrences. Caregivers gradually realize this loss and start to rely less on the care-recipient for companionship and social support.

065-01-42: I don't know when that [started]. I just realized that we were not – that I wasn't wanting to bring stories home anymore. That I didn't care whether what I heard in a musical thing, or what I read in a book, or what somebody told me, or a joke, I just didn't want to share it anymore because it wasn't going to get me any feedback. So I just began to, I don't know if it's detached. [74-year-old male caregiver]

The loss of companionship also entails the loss of emotional intimacy. The care-recipient may no longer be able to reciprocate emotionally as they did before the illness. Thus, there may

also be a loss of physical intimacy primarily due to the rupture of their emotional connection but also due to the overall decline in function and cognition the care-recipients.

065-01-42: It really is a shame to have to sleep totally separate. [74-year-old male caregiver]

The grief associated with the decline in function is experienced as the care-recipient is less able to handle routine household duties and the caregiver is required to assume them. The inability of care-recipients to carry out routine household situations is charged with emotion because it highlights to caregivers the loss of the person they knew—capable carrying out many of these routine tasks. Caregivers lament the loss of support they used to receive from the care-recipient. It is difficult for caregivers to accept that they are no longer able to count on their spouse for even simple, ordinary things.

065-02-19: He was not...So I called our plumber, and I ordered a new faucet. I just took care of it. And he was like, "well, you made a decision." And it's like, 'yeah, I did.' It feels so bad, because I don't have anybody to back me up; for me. Not to just sound like I'm feeling sorry for myself, but it's the loss of that person. [50-year-old female caregiver]

Additionally, there is change in responsibilities of household tasks within the relationship from a more equal to a unilateral exchange tilted towards the caregiver.

065-02-19: But there seems like an endless list of maintenance and things to be done, and what's really hard is that I can't, I can't turn to [my husband] in the way that I could in the past. As an equal. [50-year-old female caregiver]

Hence, caregivers not only manage the routine caregiver demands of the illness but also concurrently confront the emotional pain of the loss of a supportive partner.

Lastly, there is a general feeling of loss by caregivers for the life they had before the illness. Caregivers reflect on the changes since onset of the illness and find that their lives are not what they used to be.

P 3: 065-01-06: "Wow, it's not like it used to be." [50-year-old female caregiver]

Furthermore, they find that things are undesirable different compared to their prior "normal life."

065-01-42: There's always things that could be worse, but this is the worst I ever thought it was going to be. [74-year-old male caregiver]

Overall, caregivers understand that their “normal” life is gone with every episode of concurrent grief. They also realize they will never again be able to recover that normal life.

Grief with bvFTD Compared to EOAD

Grief occurs in all dementia subtypes since ultimately all EODs result in the same outcome with similar losses. Both caregiving groups reported the presence of grief and loss as a factor in their caregiving situation. In addition, there were no major differences in the types of grief reported between bvFTD and EOAD caregivers—both groups report experiencing anticipatory as well as concurrent grief. Additionally, grief may be different from that experienced in the late-onset dementia population given the differences between EOD and LOD. As noted in earlier chapters, EOD subtypes have been characterized as having a more aggressive disease course than the typical late-onset dementia.

065-01-07: And I realize, with her disease, or syndrome, or whatever she's got-is so new that they can't say, "Yeah, this is what's going to happen to her in six months. And in five years, she's going to be dead." They can't say that, even though I would like to know what's going to happen. [67-year-old male caregiver]

There may be differences in grief between the EOD subtypes, bvFTD and EOAD. Specifically, there may be differences in the character and intensity of the grief. There were a greater number of grief-related quotes in the bvFTD caregiver group compared to those in the EOAD caregiver group. This may indicate that, for bvFTD caregivers, grief is much more persistent than for EOAD caregivers.

There were differences in what triggered grief in bvFTD compared to EOAD caregivers early in the disease process. The grief-related issues arose due to the differences in symptomology within the dementia subtypes. Since caregivers of bvFTD care-recipients have a more rapid course (Koedam et al., 2008) and greater behavioral and emotional impairment as

seen in Chapter 1, not surprisingly, these were the principal emerging factors triggering concurrent grief in these caregivers. Similarly, in EOAD, the greater cognitive and depressive symptomology described in Chapter 1 influenced the concurrent grief EOAD caregivers may experience.

For example, caregivers of bvFTD care-recipients grieve the loss of the emotional connection they had with the care-recipient. This is consistent with the decrease in empathy observed in this bvFTD cohort. They find the illness stole for them the caring and affection they received from their spouse.

065-01-08 "I really love you." Type of thing. But, I think, at this stage, he is not capable of, I mean, it's really like a cliché of true caring for me. That's just gone. And has been gone for a long time."

This is different from EOAD where caregiver grief is due to awareness of the loss of the care-recipient's cognitive abilities.

065-02-30: Yes, speaking is what he did, and when he was not reading the communion liturgy expressively, my heart just sank. I just thought, what is the matter? [48-year-old female caregiver]

Caregivers are no longer able to connect with their spouse in the same way due to the care-recipients' decline in function, which inhibits their ability to perform their role within the relationship or eventually to recognize the caregiver and remember their shared memories. This is consistent with the decline in cognition observed in Chapter 1, "Who are Early-Onset Caregivers and Care Recipients?"

How Grief Occurs in Early-onset Caregiving

EOD caregiver grief is an extensive process that runs alongside the EOD illness and caregiver trajectory. It is not a linear cumulative process but episodic; the caregiver experiences events of grief that are triggered by the progressive decline of the care-recipient's cognitive, functional, and behavioral status. As the illness progresses and the care-recipient declines, the

caregiver confronts constant episodes of concurrent and anticipatory loss; they grieve their eventual death as well the actual losses occurring while they provide care. Since the caregiver is frequently exposed to the progressive decline of the care-recipient, they have greater awareness that the death of their loved one is unavoidable. Hence, EOD caregivers may undergo a gradual yet cumulative pre-death process.

P 6: 065-01-14: The response obviously from people we have contacted in a while, it was very sweet, but it was just for me to finally say it. It was just another step of my acceptance to what was going on...process results in the progressive acceptance of the loss. [52-year-old female caregiver]

Thus, the grief experienced by dementia caregivers may decrease in intensity as they gradually come to understand or accept the loss. These disturbing grief episodes are consistently endured by caregivers because, as the disease progresses, they have less choice and must learn to just “live with it.” Acceptance of grief, to any extent, may be a critical component for caregivers.

065-02-28: I guess it's just a wait and see game that we just have to be patient with. I don't know – I'd be nice if there was a medical pill that she could be taking so that she could be normal, but there's not, so I've got to live with it.

Caregivers may also rationalize feelings of loss and grief to better manage those emotions. Rationalizing may be an avoidance mechanism that helps them cope with the pain due to anticipatory and concurrent grief. This way they detach their emotions from the EOD caregiving situation—easing the full-blown effect of grief.

065-01-38: So I'm looking at the situation hopefully objectively, and try to make the best out of it, and try not to get too emotional about it. At the moment, I'm lucky the way it is, it's not much of a burden. We both had a pretty good time together for the last 44 years, so add another 10 years or 1 year, I don't know what the future will hold. So I don't know is that the question? I put more in than the question was worth [chuckling]. [70-year old male caregiver]

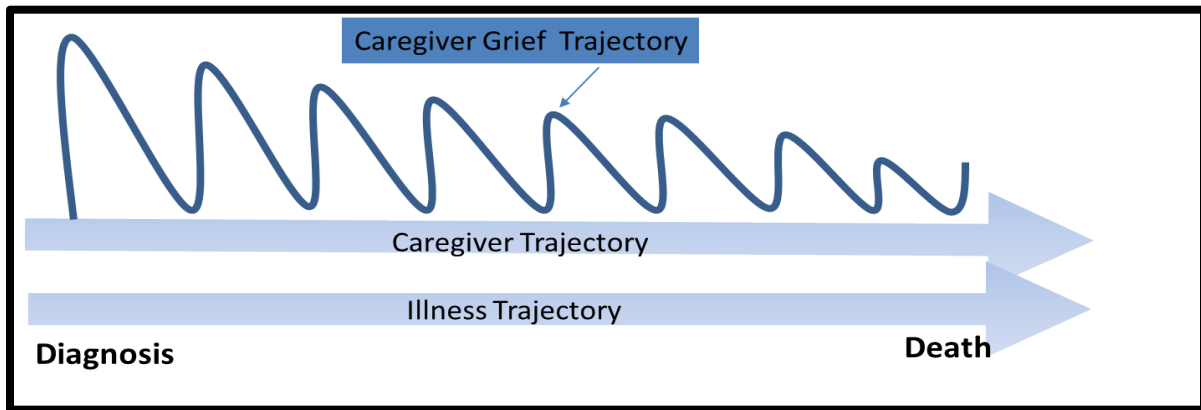
Furthermore, the incremental acceptance may also influence how caregivers experience bereavement—grief due death. At the time of the care-recipient's death, caregivers may have already dealt and accepted many aspects of grief, particularly anticipatory grief.

The grief trajectory in EOD caregiving starts before the death of the care-recipient and is intertwined with all other emotions that arise while caregiving. It is composed of multiple episodes of grief that trigger a grief reaction, which alters the caregiver's mood (Figure 6). This initial grief episode is followed by frequent reminders of the eventual death throughout the course of the illness.

065-01-47: Like hit home, or she realized...that something was going on. It's...her personality before all this was like 180 from that. She was very smart. She was an accounting supervisor at [Financial Company]. Julie's an accounting supervisor at the [LA Complex]. She was real sharp and outgoing. But now she's like...withdrawn...She's content to sit there and watch TV all day or play goofy games on the computer.

Significant caregiver events or disease milestones that occur during the caregiver experience trigger these episodes of grief.

Figure 6: Caregiver Grief Model in EOD



Although the illness will have started way before the diagnosis, the grief process starts at the time of the dementia diagnosis. The diagnosis stage may be the first time caregivers are aware of the disease outcome—the unavoidable death of their spouse due to the illness. This triggers the initial experience of caregiver grief as anticipatory or pre-death grief. This initial grief episode is followed by repeated grief episodes that are triggered by the care-recipient's decline; concurrent grief may vary in content and intensity based on the aggressiveness of the

illness trajectory.

The following are three proposed stages occurring during a single cycle of caregiver grief: (1) a period of increased grief triggered by changes in the care-recipient, (2) a compensatory period mediated by copings strategies, and (3) a baseline or stable grief status (Figure 7). The start of the grief episode is triggered by noticeable stages of change in the care-recipient. The initial trigger or first grief episode occurs at diagnosis and initiates anticipatory grief. However, the grief reaction is not sustained throughout the course of caregiving and is followed by a compensatory phase that may calm caregiver grief (Figure 7). The caregiver may then find a temporary manageable status during the caregiver trajectory. A new episode is then generated by the next disturbing change of the care-recipient or the caregiving situation.

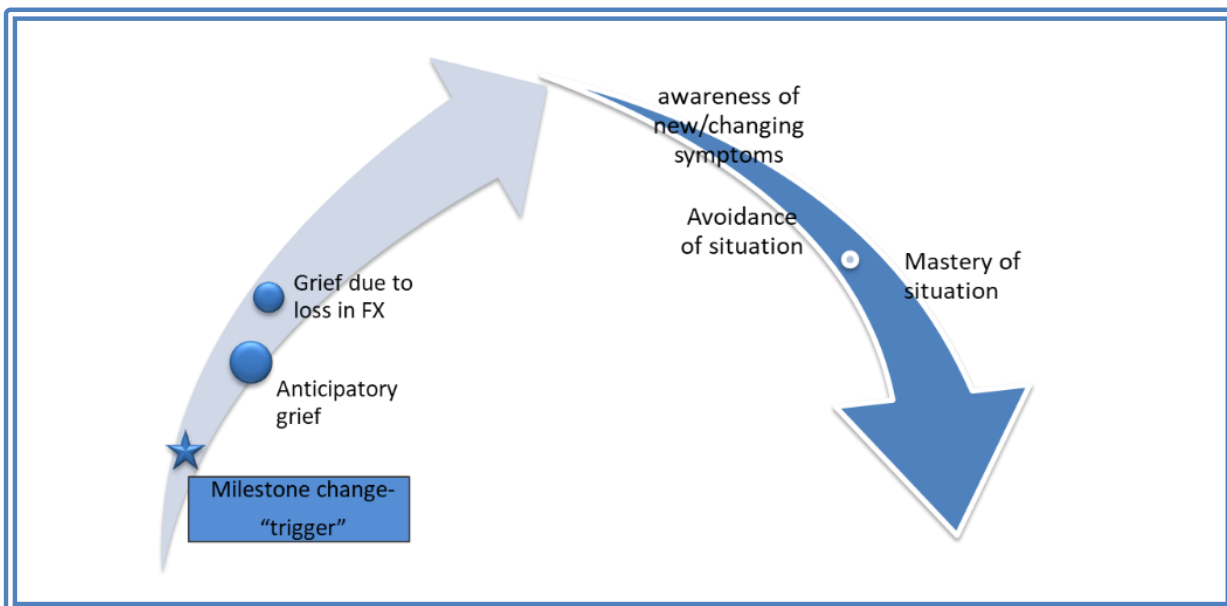


Figure 7: Changes in Caregiver Grief Episodes in EOD

During the compensatory stage, the caregivers use different mechanisms to readjust and endure the grief attack and then to find a functional grief equilibrium. They may opt to either accept or avoid the situation as a mechanism to reach stable grief equilibrium.

Avoidance may be necessary so that caregivers can manage the grief episodes at the same time as the caregiving demands. Caregivers avoid confronting full-blown anticipatory grief because the emotional effort of grief reduces their ability to carry out their day-to-day activities, which include the caregiving tasks. Many find that dealing with concurrent grief is not something they can handle while they are providing care.

065-01-07: She's just going to slowly change mentally. So as far as caregiver stuff, I have looked at it, but I haven't looked at it seriously. Because right now, I can handle it. But I can see that eventually, I'm going to need help. No doubt in my mind. [67-year-old male caregiver]

They may avoid the situation by denying the presence of anticipatory grief, which signifies the eventual death of their spouse. Some caregivers opt to grasp onto expectations of a more favorable outcome or a possible cure. They resist acceptance because it may appear as if they are giving up on their spouse.

065-01-14: "feeling like I'm not ready to say this is as good as it gets. And it very well may be, but I'm just not ready to admit that at 59 my husband's life is over. You know, I'm going to do everything I can so that he has what he needs for as long as we can provide it. I'm just not going to give up." [52-year-old male caregiver]

Hence, caregivers may struggle with acceptance because they do not want to lose hope for a cure for their spouse.

065-01-14: No, I'm having a really hard time accepting that, because I don't want to believe that there's nothing we can do. There's got to be something. Intellectually I know there's not, but emotionally I keep holding onto the magic bullet somewhere. [52-year-old female caregiver]

Additionally, denial may also bring feelings of hopelessness; they may feel they are not doing enough for their spouse.

065-01-14: I want him to have as good as life as he can and, you know. But I still feel like, you know, I just wish there was something more I could do. I hate the fact that there's not... [52-year-old female caregiver]

Lastly, these multiple, pervasive surges of grief, especially as concurrent grief, may force some caregivers to eventually accept the loss. For the most part, at later stages of the disease,

acceptance may be unescapable because caregivers may have endured recurrent anticipatory and concurrent grief.

The caregiver grief process ends with the care-recipient's death, at which time caregivers may transition to death-related grief or bereavement. This study did not capture the bereavement experience because at the time of the interview all caregivers were still providing care.

Bereavement grief is caused by the physical absence of the care-recipient and reinforced by recurrent memories of their loss. At bereavement, the grief is no longer intertwined with real-time demands of the caregiving tasks. Additionally, since for caregivers the grief process starts before the care-recipients' death, caregivers may already have some degree of acceptance of the death of their spouse. Hence, they may not experience a typical grief process at bereavement.

Chapter Summary

Grief in dementia caregiving is a major component within the overall caregiver trajectory. Beyond the burden faced by caregivers due to life and caregiving realities, they also carry a heavy emotional load, which may be greatly contributed to by feelings of grief due to loss. The emotional load is due to the distress caregivers feel while actively caregiving, responding to the eventual death of the care-recipient—anticipatory grief—and to the gradual decline and changes resulting from the illness—concurrent grief. Grief in caregiving may be a major contributor to a caregiver's mood, which in itself may help explain some of the negative consequences experienced by some caregivers.

The measure of caregiver depression commonly used with caregivers may capture the effects of the burden but also the grief associated with EOD caregiving. Detection of grief during caregiving may help shape psychological interventions that fully address caregiver depression. Thus, caregivers may benefit from support groups with an enhanced grief focus.

Longitudinal studies that follow caregivers through the caregiver course and past the care-recipient's death better define the grief trajectory; however, the proposed grief concepts of this project are limited by the cross-sectional nature of the study. However, the findings in this chapter highlight pre-death grief in EOD caregiving as a major mental health issue and suggest a model of grief among EOD spousal caregivers that can help plan effective interventions.

Chapter 9: Discussion

The research question guiding this study was to develop an in-depth understanding of early-onset dementia (EOD) caregivers' lived experience as they provide care. The initial premise was to present a snapshot of the life of early-onset caregivers. Thus, Chapter 1 provided an overview of the literature and describes the relevant theories guiding this work including the theoretical model and the research question. Chapter 2 describes the study approach and Chapters 3-8 detail the results of the research. In Chapter 3, I provide a profile of the caregivers and care-recipients using quantitative data in addition to the care-recipients' disease characteristics and caregiving outcomes. Chapter 4 describes the illness as a direct disruption and presents emerging themes of the illness process and the care-recipients' symptomology. Next, Chapter 5 focuses on the acts of EOD caregiving; it presents emerging themes describing the caregivers' illness-related and non-caregiving-related tasks and their emotional reaction to these tasks. The next two chapters, Chapter 6 and 7, describe temporality issues in EOD. Chapter 6 presents the concept of off-time life course, and chapter 7 stages the caregiver study sample based on years of caregiving to provide an EOD caregiver trajectory framework. Lastly, chapter 8 presents two major grief related categories—anticipatory and concurrent grief—and proposes an EOD grief model.

Hence, this study supplies information on the level of stress and burden of EOD caregivers and identifies and describes key stressors and rewards in their caregiving situation. Most importantly, it exposes modifiable factors in EOD caregiving, which can subsequently relieve the stress of caregiving. This study contributes to the limited literature in this uncommon caregiving population. Furthermore, it is one of few studies found to provide a comprehensive grounded theory of EOD caregivers (Johannessen et al., 2017).

This study shows how the EOD caregiver experience is lived within the caregiver's multi-dimensional life components by exploring the links between macro-level contextual factors and EOD caregiving. Specifically, it looks at the convergence of the act of EOD caregiving within the disease specificity, the caregiver's contextual factors, their life-course factors, and emotional forces. It conceptualizes caregiving as a dynamic process; since most EOD dementias are characterized by their progressive nature, caregiving should also be characterized by its evolving role. Thus, the summative EOD caregiving outcomes were found to be a result of this dynamic interwoven experience. The findings align with the "Early-onset Caregiving Model" presented in Chapter 1, which conceptualizes caregiving as being influenced by multiple trajectories.

Visibility of "invisible patient" in caregiving

This study increases the visibility of the caregivers' role, needs, stressors, and rewards. As we disentangle this interwoven EOD caregiving experience, one of the two main players in the centrality of this situation is the caregiver, the individual who provides the care—the care-recipient being the other player. However, in dementia, the needs of the care-recipient are typically prioritized and the caregiver-related needs may be often unaddressed. Some literature has named the caregiver the "invisible patient" because, although the caregiver may suffer consequences due to caregiving, (Kaiser & Panegyres, 2006; Lockeridge & Simpson, 2013; Vitaliano et al., 1991), providers often view them as a vehicle to learn information about the care-recipient or as the one to carry out caregiving tasks.

Increasing the visibility of the caregiver may help to not only address the caregiver's emotional outcomes but, subsequently, it may have a direct effect on the care-recipient's quality of life. Well-adjusted caregivers may ultimately result in a decrease of mortality and reduced institutionalization of the care-recipient (Bakker et al., 2013; Brodaty et al., 1993). Below, we

discuss the implications of this study with the aim of proposing clinical and policy relevant recommendations.

One of this study's major contributions is in showing how the unique aspects of the illness are central in defining the caregiver's lived experience. The disease specific symptoms are the driving factors defining the tasks and emotions associated EOD experience. EODs encompass distinct illnesses with diverse symptoms, different disease mechanisms, high genetic variability, atypical age of onset and a rapid progression (Mendez, 2006). Thus, EOD caregiving is indicative of the distinctness seen within the dementia subtypes.

EOD caregiving is characterized by disease subtypes

The most direct stressors in this young caregiver population stem from the illness itself. EOD has inherited disease heterogeneity with a wide range of dementia subtypes. The varied dementia subtypes within EOD are typified by distinct symptomology (Mendez, 2006; Werner et al., 2009). Hence, caregivers may be dealing with the same illness, EOD, but managing very distinct symptomology that may result in varied caregiving stressors. Therefore, since not all EOD dementias are the same, not all EOD caregiving is the same.

Thus, the varied illness symptomology may elicit burden and distress; however, it may be in response to different sources of burden or distress. In this study, we found differences within EOD caregiving based on the dementia subtype, behavioral variant frontotemporal dementia (bvFTD) vs. early-onset Alzheimer's disease (EOAD). Our findings aligned with the literature that suggests bvFTD caregivers have significantly more burden and depression than EOAD caregivers (de Vugt et al., 2006; Kaiser et al., 2007; Mioshi et al., 2013; Riedijk et al., 2006; Wong et al., 2012). Additionally, the behavioral symptoms seem to bring greater distress and burden to EOD caregivers.

However, this varied symptomology is embedded within an off-time condition. There are contextual commonalities (i.e. employment, parenting, finances) that emerged in all subtypes. However, the actual expression of these contextual factors differed depending on the disease subtype. Disease variability has been previously addressed in the caregiving management of these patients (Mendez, 2009); however, many of the attempts may fail to recognize the overall effects of disease symptoms in the caregivers' life context. Thus, this EOD situation indicates the need of typifying caregiving issues based on the subtype—particularly when providing educational and management information.

Caregivers bring life contextual factors with them

In this EOD dementia population, we found spouse caregivers bring with them midlife-related contextual factors that influence their lived experience. EOD caregivers come into caregiving with pre-established contextual factors that are prescribed not only by who they are but also by what stage they may be in their life-course. Thus, this study moves away from a task-oriented approach as described by Emily Abel (1991) and sets the caregiving tasks within the milieu of the caregiver's life—a life defined by their life course as presented in Chapter 6.

Similar to previous studies, we found that parenting (Arai, Matsumoto, Ikeda, & Arai, 2007), marital situation, employment issues, and finances were the most salient factors affecting spouse EOD caregivers (Ducharme et al., 2013). These issues are also present in the typical late-onset dementia situation; however, these issues are experienced within their present life-course. EOD caregivers are not only affected by the unexpected and unplanned direct caregiver tasks, but also by secondary, distal factors, which are themselves displaced by the onset of the EOD—these life-contextual factors continue to be at the forefront in their daily lives. Thus, comprehensive caregiver dementia evaluations should not only inventory all the direct EOD task concerns

but also consider the surrounding factors most relevant for caregivers at their present life-condition. These factors may not involve direct caregiving tasks but other non-caregiving-related tasks that affect an individual's capacity to provide care. In accordance with increasing caregiver visibility, nurse managers and physicians may benefit by not only by acknowledging the importance of the caregiver in the dementia care but also by accounting for other issues that may be affecting caregivers. This will help them better access their patients' psychosocial environment.

We found that although many of the factors concerning caregivers were pre-existing issues for caregivers, the added caregiver role might alter these factors in different ways. We found, as discussed in Chapters 5 and 7, that caregiver contextual factors are themselves transformed by the dementia situation, initially by the presence of the illness and later by its progression. Hence, it is important to conceptualize caregiver issues within the context of the illness and caregiving trajectory. This aligns with our theoretical model (Figure 1), which proposes multiple linked trajectories (illness, caregiving and the individual level factors) that continuously influence each other. The key emerging contextual factors found in this study include spousal caregiving, parenting, finances, and employment. The uniqueness of these factors is that these contextual factors are experienced by caregivers.

Spousal caregivers

Spousal-focused studies in the EOD caregiving literature are scarce despite that spouses are most often the designated caregivers in EOD. In our parent study, we found that 79 percent of all caregivers were spouses. The spouses in EOD became the primary care providers mainly due to the circumstance of the life-course situation—the spouse typically adopts the caregiving role since they are the closest next of kin at disease onset. Their existing life situation is typically not a factor when assigning a spouse the caregiving role; they are assigned the role irrespective

of their capacity to take on the responsibility. This is different than in late-onset dementia (LOD) where the caregiving role is most often performed by an adult child; the adult child assigned is the one with the least number of competing demands or the one determined by familial cultural beliefs (i.e. daughters versus sons) (Matthews et al., 1988).

This study is one of the few studies that has looked specifically at the experience of spousal caregivers in EOD (Ducharme et al., 2013; Wawrziczny et al., 2016). This is important because in EODs the couples' relationship issues may influence how the illness is experienced by the caregiver (Wawrziczny et al., 2016). The importance of the spousal relationship was corroborated in this study; the emerging grief categories in relation to both anticipatory and concurrent grief were composed of themes related to loss of relationship intimacy, home comfort, financial partner, and of spouse as confidant. Additionally, the pre-illness emotional and physical closeness of these individuals may have undoubtedly shaped their daily interactions—now transformed by the illness.

The emerging marital-related issues allude to the need of caregiver interventions that address conjugal-related issues. Specifically, it is important for providers to recognize that emotionally EOD caregivers may have lost the person that provided the most social and emotional support in their lives. Hence, many were found to be socially isolated and to have less social support.

Parenting

The different dimensions of parenting in this study exemplify the degree of alteration a caregiver's life may undergo due to the EOD. Parenting under normal circumstances may be stressful; however, during dementia caregiving it may be even more challenging. This study found that parenting under a dementia situation might involve dealing with a child that has emo-

tional issues caused by their afflicted parent's illness. Additionally, parenting responsibilities are shifted to the caregiver—they become in many aspects like a single parent.

Additionally, the illness may bring greater parenting challenges as the care-recipient attempts to continue to parent—efforts that often undermine the caregiver's rules and disciplinary actions. We found that although the care-recipient may not be equipped to parent, they often continue to make parenting decisions that influence the actions of their children. This modifiable caregiver concern emerging from our analyses has yet to be addressed in the literature.

Hence, knowing how parenting has changed for caregivers may help identify potential effective parenting interventions for EOD caregivers. This study found a need for caregiving interventions that can mitigate the inappropriate parenting attempts of the care-recipient. Additionally, EOD caregivers might benefit from supportive parenting services that include psychological help for the child. It is important to ease the effects of the disease on parenting because caregivers feel great distress when they perceive alterations in their child's life due to the illness.

Finance and Employment

Similarly, these caregivers' financial and employment situation may change due to the presence of EOD. The changes were not just the added financial burden brought by the cost of the illness. The financial challenges involved their present and future financial prospects and were a result of multiple interconnected factors. The predominant underlying factor being the caregiver's life-course stage—the timing of the illness obstructed the caregiver's ability to meet their expected financial and employment obligations and goals. Specifically, this study found that financial uncertainty may increase for EOD caregivers because the illness may involve the loss of caregiver and care-recipient wages, an increase in medical costs, and ineligibility to gov-

ernment subsidy programs. Furthermore, there may be long-term financial consequences for caregivers; they may lose years of retirement savings due to caregiving expenses. This issue is consistent with financial and employment concerns found in previous EOD studies (van Vliet et al., 2010).

These financial and employment issues influence care decisions and contribute to caregiver distress. Although financial situations may be less modifiable to immediate solutions, they provide information about the magnitude of stress EOD caregivers face. This information can help inform long-term policy priorities for the EOD community. Additionally, it indicates the need for EOD adult daycare programs that allow caregivers to continue to meet their employment obligations. We found that enabling the caregiver's work opportunities would not only provide them with financial relief but also respite from caregiving. Some caregivers found that continuing to work provided relief from their caregiving role.

Temporality as an EOD caregiver factor: Life-course and illness trajectory

This study also found that the EOD caregiver outcomes were defined by the timing of the caregiver's life stage and by the care-recipient's disease stage within the illness trajectory. Both factors speak to the dynamic aspect of EOD caregiving.

Off-time Life-course in EOD

Where caregivers may be in their life course trajectory may define the type of contextual factors they confront, the extent of the dementia education they may have, and the type of dementia resources available to them. In this study, most of the EOD caregivers were within a middle-age stage where normative expectations do not include dementia caregiving. Thus, we found EOD caregiving occurred "off-time" from these caregivers expected life-course— they

were prematurely carrying out dementia caregiving. The off-time condition was explained by the rare nature of the illness that also occurs at an unexpected time for the care-recipient—it is atypical for a person at middle age to acquire dementia. Only a few studies were found in the literature that accounted for life-course factors when looking at EOD caregiving (Ducharme et al., 2013; Manthorpe et al., 1997; van Vliet et al., 2010).

This study found the off-time condition of these caregivers led to consequences affecting many aspects of the caregivers' lives. There were indications that the caregivers' off-time condition may contribute to the burden and depression they experienced. Many of the emerging issues of distress were due to alterations to life-course stage factors such as parenting, finances, and employment as described above and detailed in Chapter 5 and 6. Additionally, since this caregiving situation is off-time from their expected life-stage, most caregivers were ill-prepared to handle its disruption in their lives. Thus, the off-time condition influenced the EOD caregiving issues they confronted, how prepared they were to handle them, and how they responded to them emotionally.

EOD caregivers' educational needs

Most of the EOD caregivers were ill-prepared when they first acquired and began to sustain the caregiver role. One of the emerging themes is the need for information—a finding consistent with the literature (Millenaar et al., 2016). The informational needs of these caregivers starts at the diagnostic phase when they are first presented with a surprising dementia diagnosis. Since EOD is a relatively rare illness, providing educational information at diagnosis is even more necessary to help caregivers understand their situation and help them adapt and manage it. Caregivers need a better understanding of the disease so that they know how to plan for it. The need for early educational interventions emerged most often for those at the early-stage phases of the ill-

ness of the trajectory discussed in Chapter 7, “Caregiving as a Trajectory.” The caregiver’s uncertainty was most often related to the lack of knowledge and control and not necessarily the illness itself. Thus, dementia educational programs or specialists may help fill this void expressed by caregivers. Additionally, clinicians may consider educational referrals during the diagnostic visit.

EOD caregiving as a progressive “trajectory”

The timing of the disease events is also important to understanding the caregiver experience in real-time. This study found the caregiver trajectory might be interdependent on disease progression. Hence, the dynamic nature of the disease indicates an equality changing or progressing caregiver situation. Thus, greater understanding of the illness trajectory and its effect on the caregiver role may help better define caregiving stages. This may help meet the informational needs of EOD caregivers whose major source of distress is the uncertainty elicited by the lack of information.

In Chapter 7, “Caregiving as a Trajectory,” the study profiled caregivers based on the care-recipients’ disease stage as an initial attempt to understand the caregiver trajectory. This is different from the Caregiver Career presented by Aneshensel et al (1995), which proposes a caregiver trajectory along a much more extensive period of caregiving (Aneshensel et al., 1995). However, the premise of the proposed trajectory is similar where it accounts for the progressive nature of the dementia. The proposed trajectory presented in this study focuses on the two initial phases of the Caregiver Career, “role acquisition and “role enactment,” the second as it relates to those not institutionalized. Furthermore, the proposed “EOD Caregiving Trajectory” is relatively specific to EOD as it takes into account EOD-specific disease changes and the caregiver’s life

contextual factors. There is great utility in refining an EOD caregiver model because it may provide EOD caregivers information on what to expect during their caregiving experience.

Complexity of caregiving outcomes in EOD

The emotional outcomes of caregiving are interwoven with burden, caregiving depression, and grief. The caregiver's emotional status results from a convergence of all factors affecting caregivers such as illness, caregiving task, contextual factors, and perceived losses. This study corroborated the literature where these EOD caregivers were found to experience distressing levels of burden and higher than normative depression scores (Kaiser and Panegyres 2006). Thus this study, through a grounded theory approach, attempted to disentangle the type of issues influencing the caregivers' emotions with the goal of identifying intervening factors.

Grief-related issues were identified in Chapter 8, "Caregiver Grief in Early-onset Dementia," as contributing to the EOD caregivers' emotional well-being. This study reported the prevailing presence of grief throughout the caregiver trajectory as concurrent grief. Thus, a better detection of grief during caregiving is recommended to better assess its effect during the caregiving process. Additionally, EOD caregiving support groups may be more effective if they address grief-related concepts.

Additionally, although the findings are tilted towards negative consequences of caregiving, there were some emerging positive factors in EOD caregiving. We found that caregivers, particular early in the disease process, gained enjoyment from spending time with care-recipient. At the later stages, caregivers gained pleasure from their mastery of the caregiving role—they felt that they developed meaningful, transforming personal qualities.

EOD spousal caregivers are a high-risk caregiver population

In sum, this study finds the lived experience of EOD caregiving is multi-dimensional. Furthermore, the off-time component of EOD may add a greater risk of negative outcomes. Thus, we propose that EOD spousal caregivers can be considered a high-risk caregiver population. EOD caregivers are known to have significant detrimental consequences such as greater burden and depression due to the EOD (van Vliet et al., 2010) Our results support this finding of a high-risk population. First, these caregivers can be considered highly “burdened” based on the Zarit Burden Inventory. Second, we found the atypical circumstance of caregiving limits their access to resources. Third, being off-time, they lack proper information to understand the illness and how to manage the care-recipient. Lastly, these caregivers may have a greater number of competing demands that add to their caregiver burden. The culmination of these factors suggests this group of caregivers maybe at higher risk of caregiver burnout compared to typical LOD caregivers. Subsequently, these caregivers may be more likely to opt for institutionalizing care-recipients. This indicates the need for special consideration of EOD caregivers within a dementia policy agenda.

Limitations

This was a retrospective, cross-sectional, qualitative study that can only describe the lived experience of this group of EOD caregivers—its findings are not intended for generalizability to the EOD population. This is consistent with qualitative studies designed to describe a phenomenon with the purpose of theory building. The cross-sectional and retrospective aspects of this study bring inherited limitations that further compromise the results. For one, this study cannot summarize how time affects the lived experience of EOD caregivers. Secondly, there may be recall bias—some of the questions relied on the caregivers’ recalling events and situations that oc-

curred in the past. Nonetheless, findings from this study may generate new research questions and inform caregiver surveys and other quantitative measures than can be tested with larger studies.

The convenience nature and size of the sample as well as absence of a comparison LOD group further compromise the generalizability of the study results. The study investigated an existing sample from a parent study that only recruited patients from a dementia specialty clinic. The clinic serves a selective population of patients and caregivers who have financial and educational resources. Thus, this caregiving population is disproportionately upper-middle class, white, and highly educated. However, due to the uncommonness of the EOD illness, overcoming these recruitment limitations remains challenging.

The inclusion/exclusion criteria of this study targeted care-recipients who were relatively early in the disease process. Hence, this study did not capture the experience of caregivers providing care at the advance stages of the disease. In addition, due to the uncommonness of the illness, only a limited number of participants qualified and eventually enrolled in this study, which yielded a small sample. This is a common issue across the EOD literature where most studies only report on samples ranging from 12 to 102 (van Vliet, de Vugt et al. 2010). Lastly, because the main purpose of the parent study was to compare bvFTD and EOAD, a late-onset sample was not available for comparison. The late-onset comparison would have helped contrast the EOD experience with another dementia group to better identify and characterize the life course stage and off-time related issues presented in this study.

Nevertheless, this novel study explores caregiver components that have not been extensively studied in the EOD caregiver literature. For example, it explores the effects of life-course

timing and contextual factors, as well as the effects of grief in this EOD population. Additionally, this study benefits from the parent study, which enrolled a cohort of well-characterized EOD participants. The care-recipients underwent an extensive diagnosis process, which provides validity to the presence of the illness—the illness being the main primary caregiver stressor. Furthermore, our EOD care-recipient sample was characterized based on their behavioral, psychiatric, and cognitive symptomatology as well as functional ability. The information was triangulated with qualitative measures, increasing the trustworthiness of our findings. Furthermore, the study neurologists subtyped the dementias (i.e. bvFTD vs AD), allowing comparisons within the sample of symptoms (i.e. behavior versus memory-related stressor). Overall, this study's major strength is its access to this unique, understudied population; there are only a few centers across the country with the access to study EOD caregivers.

Policy Implications/Recommendations

The implication of this caregiver study for practitioners and policymakers is that it characterizes the complex, multi-layered lived experience of EDO caregivers. Furthermore, the grounded theory approach allows the emergence of the most salient issues affecting these caregivers, which helps identify prevailing clinical and policy needs.

For practitioners and policymakers, this study highlights that EOD dementia caregiving, although uncommon, may have serious consequences for the well-being of those providing the care as well as those afflicted with an EOD. Thus, understanding the experience of EOD caregivers becomes crucial to the care of the EOD patient and the well-being of those around them. Specifically, the maladaptation of EOD caregivers may limit the ability of care-recipients to stay at their homes—speeding-up time to institutionalization. Institutionalization has been associated with detrimental effects on the care-recipient's quality of life and mortality (Brodaty,

McGilchrist, Harris, & Peters, 1993). The knowledge of the underpinnings of EOD caregiving presented in this study will both increase awareness and help focus service provision and policies within the EOD dementia caregiving arena.

At the micro level, this study finds that the illness trajectory drives many of the stressors experienced by EOD caregivers. Specifically, this study found that EOD has high variability resulting in a wide-ranging symptom manifestation that may affect caregivers in different ways. Thus, for practitioners, this emphasizes the need for effective management of patients, which may result in both caregiver burden relief as well decreased institutionalization. Furthermore, this knowledge encourages practitioners to work closely with caregivers to identify problem behaviors with the goal to develop and implement both pharmacological and behavioral management interventions that may reduce troublesome behaviors.

Additionally, the high burden associated with EOD points to the need of respite services for caregivers. This is especially concerning for this early-onset population. The current respite system is directed towards older and less behaviorally disturbed patients, which fails to accommodate the needs of younger victims of this disease. At the program level, this information raises awareness of the need for both caregiver support and respite services that are equipped to service younger and highly behaviorally disturbed individuals. The knowledge gained from this study of EOD caregivers provides detail on prevailing EOD caregiving themes, information which can help design services for EOD caregivers.

EOD resources are not appropriate

This study corroborated previous findings that most caregiving resources available are tilted towards the needs of those caring for the elderly. Hence, we find a need in EOD for suita-

ble respite services, particularly for adult-day care or in-home help for EOD care-recipients who are younger, more energetic, and exhibit a greater number of severe psychiatric symptoms. In the elder dementia population, respite services have been found to be highly effective in providing caregivers time away, easing caregiver burden (Gaugler et al., 2003). However, these type of services are scarce, costly, and often not available for younger patients (Alzheimer's Association, 2006). This study particularly highlights that it is the absence of existing age-appropriate services that most concerns this population. Notably, caregivers in this EOD study sample had economic resources and were highly educated, yet they still reported many challenges when accessing EOD resources. Thus, EOD caregivers may not benefit by only increasing access to the existing caregiver infrastructure. They need EOD programs that take into account the peculiarities of the EOD illnesses and the contextual circumstances of these caregivers. Thus, for policymakers and researchers, it is imperative they consider the unique challenges entailed in EOD caregiving and to appropriately propose innovative programs.

The lack of appropriate services for both EOD caregivers and their care-recipients is a consequence of being off-time in their expected life-course (Gibson et al., 2014; Millenaar et al., 2016; van Vliet et al., 2010). In this study, a key emerging issue was the absence of services for off-time “young” caregivers. Many caregivers tried existing dementia resources and found they were designed to address the needs of older people. Thus, being a young off-time caregiver is problematic because of a limited network of appropriate resources—EOD caregivers often experience unmet needs. Thus, this work has policy implications for existing agencies such as the Alzheimer’s Association; this study suggests the need to restructure their caregiver support services to effectively address the needs of spousal EOD caregivers. Although the prevalence EOD

is low, EOD caregivers may suffer greater detrimental consequences compared to typical LOAD caregivers—impacting EOD caregiver’s ability to sustain this role.

The resource needs of EOD caregivers are twofold: (1) services for the care-recipient that can provide caregiver respite and (2) caregiver support groups. In this study, many caregivers found available services, such as adult-day care, to be inadequate, particularly for those care-recipients that exhibit prominent behavioral disturbances. Additionally, the literature notes that EOD care-recipients may not adapt well to conventional adult programs because they find other participants to be different than they are and the activities may not be physically challenging for them (Millenaar et al., 2016).

The caregiver-focused dementia resources such as support groups were found to be equality biased towards the needs of older individuals. Furthermore, many caregivers resisted joining dementia support groups due to their own biases. Many caregivers perceived dementia groups as not being appropriate or helpful because they see themselves as possibly “sitting around listening to a bunch of old grannies or grandpas.” Additionally, due to competing demands such as parenting and employment, caregivers found most support groups were not convenient for them to attend.

Thus, to start addressing the needs of EOD caregivers, policy is needed that advocates for EOD- specific caregiving services for both care-recipients and caregivers. These programs would need to consider the off-time life-course condition of EOD caregivers. Policymakers may help advocate for increased funding of existing dementia networks, enabling them to carve-out EOD focused services. This would encourage existing respite and caregiver programs to begin offering formal EOD support services— moving away from the current ad-hoc services offered to

EOD caregivers. In the long-term, this effort could set the groundwork for EOD-specific respite programs for this disfranchised dementia population.

EOD caregiving alters life contextual factors

This study also proposes that EOD caregiver support services should be reflective of caregiver's contextual reality. This study informed the overall context of EOD spouse caregivers. EOD caregivers undergo major life alterations due to the dementia that jeopardize not only their emotional wellbeing but also their livelihood. They may confront financial and employment issues that may bring detrimental consequences to their household as they eventually become the sole provider of the household. Many caregivers are actively parenting and managing all household obligations. Contextually, the presence of the illness is a major disruption for vulnerable households (i.e., with less economic resources) and could have catastrophic consequences. This is important because EOD caregivers may be at a higher risk of caregiving burnout. Hence, a sole focus on disease-specific caregiver stressors may not be sufficient to mitigate this outcome. Thus, for policymakers and dementia advocates, this study presents evidence supporting a holistic view of EOD caregiving. It indicates the need to address not only the direct caregiver stressors but also the daily life factors that greatly contribute to their ability to sustain the EOD caregiving situation.

This study's findings can help program planning efforts in EOD caregiving by informing the program design. For example, this study found the need for EOD caregiver-support groups during off-work schedules to accommodate most EOD caregivers who are actively participating in the workforce. Thus, support services using different modalities may need to be considered as a way to address the needs of EOD caregivers. For example, some studies report using telehealth

videoconference support groups (O’Connell et al., 2014) and online forums (Rodriquez, 2013; White, 2016).

Caregiver policy focused on alleviating the contextual off-time reality of EOD caregivers is also needed. For example, employment protection regulations that allow caregivers time to meet their caregiver duties while employed. Also, parenting and household assistance programs are called for that help reduce the burden from indirect non-caregiving tasks, which many EOD caregivers simultaneously handle. Changes in public assistance programs are needed, such as Medicare, where age-restrictive criteria limits the access of young caregivers to needed resources.

This work can have major implications on what future support efforts may be considered for this vulnerable EOD caregiving population. Although much research is still needed, it exposes the complexity of EOD caregiving and the need for EOD tailored programs.

Future Research

For future research, it would be valuable to have a greater understanding of how the care-recipients ‘symptomatology may affect the caregiver. Additionally, longitudinal studies that provide information on the long-term consequences of caregiving are necessary since these specific dementias have a progressive occurrence. Most importantly, patient and caregiver intervention studies are greatly needed—the current EOD caregiving situation is precarious for those involved.

The findings presented in this study can help define the direction of future research in this field. There is a need to substantially refine the research agenda for EOD caregiving, specifically by providing a profound understanding of factors influencing the EOD caregiver experience. My

research plan is to continue to deconstruct the following major areas that may be central in the understanding the EOD caregiver lived experience: (1) the caregivers perception of the illness, (2) the acts of caregiving, (3) the effects of temporality in caregiving, and (4) the emotional consequences of EOD caregiving.

The first, the caregiver's experience of the illness trajectory, described in Chapter 4, can provide an account of the long diagnostic process and emerging symptoms. This research area will outline the peculiarities of the primary disturbances from the caregivers' perspective, which is often different than that set forth by the biomedical establishment. This information can contribute to a much-needed comprehensive diagnostic model that is inclusive of the Pre-diagnosis stage, which highlights key symptoms. It is also important to explore further the diagnostic process—found in this study to be long and burdensome for caregivers and care-recipients. Greater knowledge of the illness process may have important implications for practitioners, information which may equip them to better identify EOD situations. Additionally, this research is essential because it can inform practitioners about what caregivers find to be important areas of disease management—alleviating the burden of these caregiver-identified symptoms may be effective in reducing caregiver distress.

Secondly, and as important, is the need to account and understand the acts entailed in caregiving. This work starts to identify and describe them, presenting them as caregiver-related and life-related tasks. There is a need to further define these tasks and identify their influence in caregiver emotional outcomes. This preliminary descriptive data can help inform the development of an EOD-specific burden inventory scale, a much-needed tool that may help evaluate caregivers. Furthermore, caregiver tasks are a modifiable component in the caregiver situation and may be the central and most promising area for future caregiver intervention studies.

Thirdly, temporality issues are central in EOD caregiving. The EOD caregiver experience as an atypical life-course occurrence can help inform and test theoretical life-course frameworks. This area of research can expose the consequences on non-normative life events on a person's life context—information that can expand policy benefiting EOD caregivers by providing policymakers information on gaps in existing policies, such as government services eligibility criteria or family leave needs of employed caregivers.

Lastly, the most impactful finding in this study is that it exposed the complexity of the emotional consequences of EOD. This study starts to deconstruct emotion in caregiving by going beyond typical measures such as burden and depression; it looks at the effects of anticipatory grief in EOD. There is a need to better understand how anticipatory grief affects the caregivers so that effective psychosocial interventions can be studied. Also, this study is not able to determine the severity of the emotional status of these caregivers due to the lack of a late-onset comparison group. Adding a late-onset comparison group will help describe not only the severity but also highlight EOAD-specific issues that contribute to their emotional status.

There are also external opportunities to further move forward the EOD caregiver agenda. For example, the effects of the illness on the caregiver can be readily studied by greater coordination with established longitudinal and consortium studies to include caregiver-level outcome measures. For example, this caregiver study benefited from available care-recipient level information that was linked to the parent study. Many NIH sponsored national Alzheimer's Coordinating Centers across the country collect extensive data on afflicted individuals. EOD Caregiver researchers could benefit by exploring greater partnership with existing dementia research centers or individual investigators to better coordinate research efforts.

The progressive nature of illness calls attention to the need for more longitudinal studies. Longitudinal studies in EOD caregiving are extremely rare, which limits our ability to truly explore how the EOD caregiving situation affects caregiving. Specifically longitudinal research is needed to identify factors that may either help or inhibit a caregiver's ability to adapt to their EOD caregiving role.

Caregiver-focused interventions should consider both EOD specific respite and support services. Support group interventions could entail accessible groups that account for these EOD caregivers' multiple competing demands. They need to have more than a task management approach; they need to address their emotional needs as emotional distress was a key unresolved issue observed in this study. Specifically, EOD caregivers could benefit from psychosocial interventions that target anticipatory and concurrent grief related issues—caregiver support groups with an enhanced focus on the grief experienced during caregiving. However, the timing of these interventions should also be considered—not all caregivers may be emotionally ready to confront these sensitive topics.

Chapter Summary

In sum, this study provides a glimpse of these caregivers' lived experience. It places the off-time caregiving tasks and distinct illness within the context of their everyday realities. Additionally, it exposes the emotion underlying this experience. It also highlights the lack of support available to sustain this untimely interruption in their lives. Moreover, it demonstrates the dynamic interplay between all of these factors. This study puts forth that EOD caregivers are individuals that traverse life with an enormous complex burden—they are truly besieged individuals.

Appendices

1. Appendix A: IRB Approval
2. Appendix B: Baseline Interview Guide

Appendix A: IRB Approval



University of California Los Angeles
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 General Campus IRB: (310) 825-7122
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APPROVAL NOTICE

DATE:	5/24/2017
TO:	MARIO MENDEZ, MD, PhD NEUROLOGY
FROM:	JAMES MC GOUGH, MD Chair, MIRB3
RE:	IRB#10-001097-CR-00007 2017 Review for IRB#10-001097 Study of Social Behavior and Emotion in Frontotemporal Dementia, Alzheimer's Disease and Controls Version: Fax LAR consent, New imaging students

The UCLA Institutional Review Board (UCLA IRB) has approved the submission listed below. UCLA's Federalwide Assurance (FWA) with Department of Health and Human Services is FWA00004642.

Submission and Review Information

Type of Submission	Continuing Review
Type of Review	Expedited Review
Approval Date for this Submission	5/24/2017
Expiration Date of the Study	5/23/2018
Funding Source(s)	1) NIH - MISCELLANEOUS AGENCIES AND DEPARTMENTS <i>Grant PI:</i> MARIO MENDEZ <i>Grant Title:</i> Multidisciplinary Study of Social Behavior and Emotion in Frontotemporal Dementia <i>Grant Number:</i> 1R01AG034499-01

Specific Conditions for Approval

-- Data Analysis Only - the remaining research activities are limited to data

Appendix B: Baseline Interview Guide

I. STUDY PARTNER FOCUSED INTERVIEW

ADMINISTERED BY: _____

DATE ADMINISTERED: _____

1. Background

- a. What kind of relationship did you have with your relative before the onset of the disease?
How has your relationship with your relative changed since the onset of the disease?
- b. What social networks do you belong to?
- c. What resources would you say you have available to help you care for your relative?

2. Primary Stressors

- a. Which cognitive difficulties of your relative most affect your everyday life? In what ways?
- b. Which behavioral issues of your relative most affect your everyday life? In what ways?
- c. How much help does _____ need in day-to-day activities?

3. Secondary Stressors: Role Strains

- a. How has the disease affected your relationship with other family members?
- b. How has the disease affected your ability to work outside the home?
- c. How has the disease affected your financial status?
- d. How has the disease affected your relationships with friends and other social groups?

4. Secondary Stressors: Intrapsychic Strains

- a. How has this role affected you personally?
- b. How has this role affected the way you view yourself?
- c. Have you gained anything through this process?

5. Coping Strategies

- a. What specific things have you done to manage the difficulties caused by taking care of someone else?
- b. In what ways have you tried to adjust your thinking?
- c. What have you done to manage stress related to the disease?

6. Social Support

- a. Do you have anyone (agencies, individuals) who helps you with tasks or responsibilities related to caregiving?
- b. Do you have access to individuals who understand you? Express care? Are trustworthy? Are uplifting?

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