

DEATH & TAXES: A GROUNDED THEORY OF FINANCIAL STRESS, COPING, AND  
DECISION-MAKING AMONG DIVERSE FEMALE-IDENTIFIED DEMENTIA CARE  
PARTNERS

by

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## ABSTRACT

As the population longevity increases, so does the demand for caregivers. The cost for providing unpaid care also continues to increase significantly. Given the weight of this financial burden, it is imperative scientific and clinical communities strive to understand objective income and financial stress, and how these impact decision-making and planning for end-of-life care. Moreover, a nuanced understanding of the component parts of financial stress and subsequent behavior is necessary in order to develop and implement effective interventions. This study employed a constructivist grounded theory approach to investigate the lived experience of financial stress, coping, and decision-making among 18 female identified spousal dementia caregivers. Although end-of-life financial planning was identified as one of the greatest stressors, results revealed caregivers consistently employed avoidant coping and disengagement from end-of-life financial decision-making. Moreover, findings suggest financial stress is a complex and nuanced construct that manifests at each stage of the stress and coping process. Three categories and 13 themes were identified. Implications for scientific advancement and intervention development are discussed.

## DEDICATION

Robert McNair who gave me opportunity.

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Rebecca Allen who gave me perseverance.

My mother who gave me grit and passion.

And finally, to Gwen and Ed, whose love story inspired this journey.

## LIST OF ABBREVIATIONS AND SYMBOLS

$M$	Mean: the sum of a set of measurements divided by the number of measurements in the set
$N$	Sample size
$p$	Probability associated with the occurrence under the null hypothesis of a value as extreme as or more extreme than the observed value
$r$	Pearson product-moment correlation
$SD$	Standard deviation: amount of variation or dispersion of a set of data values
$<$	Less than
$=$	Equal to
CG	Caregiver
PWD	Person with Dementia

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## INTRODUCTION

As the population longevity increases, so does the population of individuals living with Alzheimer's disease and other dementias. One of the first problems in daily living that may become readily apparent is change in financial management and financial decision-making. In fact, financial capacity may be an early indicator of cognitive decline (e.g., Marson, 2001) placing individuals with cognitive impairment at risk for financial mismanagement or exploitation (e.g., Lichtenberg, 2016). Family members often transition into a role in which they assume financial management and financial decision-making among other caregiving duties upon detection of cognitive decline. This is often accompanied by growing care-related costs (e.g., Harper, 2014). One report estimated the average annual cost of caregiving for an older adult, including medical care, in-home formal, and informal care, to be between \$41,689 and \$56,290 (Hurd, Martorell, Delavande, Mullen, & Langa, 2013), and these costs are typically higher for dementia caregivers (Zhu et al., 2015). The Alzheimer's Association has released its annual Facts and Figures Report (2020) estimating the lifetime cost of caring for an individual with dementia to be \$357,297, of which approximately 70% is borne by families either out-of-pocket (e.g., long term care) or through unpaid care. It is likely that the stress associated with these costs and financial management demands, in addition to the burden accompanying such role transitions, affects: 1) the caregiver experience, 2) the caregiver-care recipient relationship, and 3) the provision of care. Therefore, understanding the subjective appraisals and associated effects of these costs and how finances are managed is an important public health, economic

and legal endeavor. These effects have yet to be comprehensively described, measured, or investigated, and may yield scientific insights for theoretical models and clinical insights for points of intervention delivery. This study aims to describe the nature of caregivers' lived experience of financial stress and how it manifests during the decision-making process. It further aims to explore potential convergences and divergences in study phenomena across income level.

To establish the need for this study, the introduction will provide an overview of research investigating financial stress and strain among caregivers and reviews of traditional and contemporary stress theory (e.g., Lazarus & Folkman, 1984; Pearlin, Mullan, Semple, & Skaff, 1990) decision-making models (e.g., Miller, Whitlatch, & Lyons, 2016), and the theory of caregiver and care recipient dyadic identity development (Coeling, Biordi, & Theis, 2003) as they pertain to the caregiver experience. Finally, gender and power will be discussed as they relate to health disparities resulting from the differential impact of Alzheimer's disease and related dementias on women.

### **Financial Stress and Strain**

In order to investigate financial stress within the context of dementia caregiving, there must first be an understanding of the varied operationalization of stress, strain and stressors among researchers. While there is substantial literature to support the operationalization of the term 'stressor', there has been a great deal of disagreement and inconsistency in the operationalization of stress and strain (see Cooper et al., 2001 for an overview). A stressor is commonly defined as a stimulus that produces a stress response in the majority of individuals (e.g., Kahn & Byosiere, 1992; Thatcher & Miller, 2003). There are two broad categories of conceptualization of the term stress—response-based and stimulus-based. Early definitions of

response-based stress (e.g., Selye, 1936) indicated it was the outcome of a disturbance to one's environment. Alternatively, stimulus-based definitions (e.g., Lazarus, 1966) defined stress as the input variable that does the disturbing. More contemporary views consider stress as an intervening cognitive and emotional variable that operates between a stimulus and a response (e.g., Lazarus & Folkman, 1984). This transactional model strives to understand and illustrate psychological mechanisms underpinning subjective cognitive appraisals of stress-inducing events. Some conceptualizations stray from these contemporary views of stress to include two variations of 'perceived stress' (e.g., Thatcher & Miller, 2003). More specifically, this includes an individual's perceptions of 1) the task demands and 2) self-perceptions of one's ability to cope.

Responses to stressful events vary greatly and can range from positive and beneficial to negative and detrimental. For example, Selye's (1976) model distinguished between motivational stress (i.e., eustress) and harmful stress (distress). Eustress is a response to a stressful event in which an individual is motivated and mobilized to expend more resources to maintain homeostasis. Distress, or strain, is often considered a negative response to a stressful event when an individual can no longer maintain functioning or effectively engage coping mechanisms (e.g., Cooper et al., 2001, Kahn & Byosiere, 1992). Strain, which exists along a continuum, is only one of many responses an individual might have to a stressful event, and not all responses to stressful events result in strain.

While it is widely recognized that caregivers experience a variety of stressors that affect their mental and physical health and wellbeing (Chiao, Wu, & Hsiao, 2015; Martin, Gilbert, McEwan, & Irons, 2006; Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013; Pinguart & Sörenson, 2003, 2006; Schulz & Martire, 2004), there is a paucity of research surrounding their

experience of financial stress, financial strain, or how this interacts with or influences financial decision-making and planning (George, 2003; Kahn & Pearlin, 2006). However, there is empirical evidence suggesting financial strain, specifically, may be a pivotal chronic stressor linked to physical and mental health morbidity experienced later in life (Kahn & Pearlin, 2006; Lincoln, 2007). There is also evidence suggesting financial difficulties foster strain in relationships (e.g., Kinnunen & Feldt, 2004; Robila & Krishnakumar, 2005). While there is some evidence regarding the efficacy of interventions targeting married couples experiencing financial and marital strain (e.g., seeing a financial counselor; e.g., Knuckey, 2003), this has not been examined within the context of dementia. It is plausible there are unique challenges that emerge for individuals confronted with cognitive decline and role transitions, and current models of integrated care and interventions may not be suited to meet their unique needs.

### **Financial Stress and Income**

Efforts to meet the increasing demands for caregiving seem to have manifested in a rise in familism (Silverstein & Wang, 2015). This has brought attention to the struggles of many lower and middle class families who cannot afford palliative care services that allow their loved ones to live and die comfortably in place. Therefore, more affluent families who can afford such services seem to be able to exert more control over their caregiving context (e.g., Bruhn & Rebach, 2014). For example, a study conducted by Caplan and Schooler (2007) revealed low socioeconomic status (SES) may decrease one's perceived control beliefs, which subsequently influences the likelihood of utilizing effective financial coping strategies. While financial hardship and low SES are associated with an array of negative physical and mental health outcomes (e.g., Peirce, Frone, Russell, & Cooper, 1996; Skinner, Zautra, & Reich, 2004), and more affluent individuals might have access to better services or perceive more control, it is

unclear how this manifests among dyads coping with cognitive impairment. Moreover, this research does not account for shifts in financial capacity and decision-making. It is plausible that an individual who is more affluent and historically has perceived more control might have more difficulty adapting to such stress compared to a less affluent individual who has potentially spent more time adapting to financial stressors or lower levels of perceived control and are therefore acclimatized to such situations.

Stress Theory (Lazarus & Folkman, 1984), specifically, delineates between an objective stimulus and subsequent subjective appraisal. These subjective appraisals vary as a function of individual differences that include personal characteristics, historical and cultural context, and current circumstances. Appraisals of stressors can be deconstructed into two areas: 1) perceived threat to homeostasis or well-being, and 2) evaluation of available resources to serve as a buffer to said threat. In this framework, financial strain, specifically, would manifest when an individual believed they did not have the available resources to meet financial demands.

Available resources transcend objective income to include other things such as strong financial management and problem-solving skills as well as effective emotion regulation. Therefore, despite the lack of research, it is plausible that individuals transitioning into a role where they begin to assume financial management and decision-making responsibilities for a care recipient may foster or exacerbate the experience of financial stress.

Many conceptual models that describe these caregiver experiences (e.g., Stress Process Model; SPM; Pearlin, Mullan, Semple, & Skaff, 1990) typically include financial responsibilities as an indirect stressor, failing to consider financial stressors directly related to the provision of care. Additionally, there is a lack of consensus regarding conceptualization, operationalization, or measurement of financial stress across research and clinical settings, making it difficult to

attribute outcomes to a financial stressor or its subjective appraisal. Existing studies often use household income or SES as an index for financial stress, which is problematic for several reasons. While there is evidence to suggest SES is related to morbidity and mortality (e.g., Kahn & Pearlin, 2006) such that lower objective income predicts higher rates of morbidity and mortality, there are aspects of financial stress not accurately represented by objective income (e.g., an individual with higher SES might report more financial strain than someone of lower SES). Therefore, objective income alone is not a sufficient index for financial stress. For example, Sun and colleagues (2009) found that perceived income inadequacy predicted depressive symptomatology and self-reported anxiety in Alzheimer's caregivers, while objective household income predicted neither. Moreover, it is plausible that individuals with greater financial assets have more to lose when experiencing financial decision-making transitions. It is equally plausible individuals with lesser financial assets have adapted over time to the effects of financial stressors, thus experiencing little to no stress. This is consistent with the notion that money has a subjective value that is different from its nominal value (see Gärling, Kirchler, Lewis, & Van Raaij, 2009, for a review). Unfortunately, the experience of financial stress has not been investigated across class or income level; therefore, it is unclear how and if financial stress manifests differently as a function of income. This is important within the context of dementia considering aforementioned cost and role transition.

### **Financial Management and Decision-Making**

While decision making has been investigated regarding driving (e.g., Adler, 2010), medical treatment (e.g., Sessums, Zembrzuska, & Jackson, 2011), end-of-life care (Haley et al., 2002), and placement (Caron, Griffith, & Arcand 2005), there is a dearth of research regarding care-related financial decision-making in this population (Boyle, 2013). Some dyads might



engage in a more shared decision-making model or supportive decision-making model or others might engage in substituted decision-making (Miller, Whitlatch, & Lyons, 2016). The theory of caregiver and care recipient dyadic identity development suggests that both parties must negotiate the dyadic identity, often at the expense, to some degree, of individual identity (e.g., decision-making; roles in care, financial management; Coeling, Biordi, & Theis, 2003). This exerts differential influence on feelings of autonomy, meaning in life, and well-being.

This process becomes more complex in dyads and might manifest via power dynamics regarding autonomy in decision-making. The ability to exercise control and choice is essential for feelings of autonomy and associated quality of life (Heckhausen & Schulz, 1993; Kane, 2003; Samsi & Manthorpe, 2013; Stevens et al., 2011). The initial transition into a dyadic relationship in the context of dementia, for both parties, is accompanied by fluctuations in perceived and actual control, choice, and feelings of autonomy and self-efficacy as they solidify a new or refined dyadic coping profile (Coeling, Biordi, & Theis, 2003). These fluctuations directly influence a sense of role and identity. A central tenet of theories regarding control, agency, and coping, is that individuals value and prefer choice (Bandura, 1997; Brehm, 1966, Deci & Ryan, 1985; Seligman, 1975). In this context, choice can be regarded as the ability to make a preferred selection among two or more options (Stancliffe, 2001). Individuals diagnosed with Alzheimer's disease begin to experience difficulties in cognitive domains necessary for effective decision-making including memory, judgment, and reasoning, even in the early stages. This is important because facets of capacity may be preserved while only executional abilities have deteriorated; therefore, an individual may make their decision-making wishes known well into their disease progression (Boyle, 2008, 2013; Collopy 1995, Marson, 2001).

In one notably relevant study, Samsi & Manthorpe (2013) conducted a phenomenological study in which they interviewed 12 dyads (one person with dementia and one caregiver) four times over one year to examine the experience of general decision-making among care partners. They found that when caregivers gradually take on decision-making for individuals with cognitive impairment, it has the potential to increase stress associated with determining their relative's decision-making capacity and weighing options regarding their best interests. Specifically, decision-making discourse evolved over time where everyday decisions, at first, were made jointly among care partners, but were made more wholly by the caregiver later. Most importantly, they found that caregivers emphasized the importance of decision-specific contexts.

### **Gender, Power, and Financial Decision-Making**

Gender and power dynamics are also important constructs of consideration within the context of dementia caregiving and financial stress and decision-making (Boyle, 2013). There has been an increased interest in the role of gender within the context of caregiving in recent years (Baker & Robertson, 2008; Pinquart & Sörensen, 2006) as women are disproportionately affected by dementia (e.g., Erol, Brooker, & Peel, 2015). A recent global review (Erol, Brooker, & Peel, 2015) cited that more women live with dementia, the prevalence is higher for women, and symptoms they live with are more severe. They also reported women make up approximately 2/3 of the population of informal primary caregivers. They argue that there is currently very little research focusing on these apparent gender issues. Stress and coping theories propose that women are more likely to be exposed to caregiving stressors, and are likely to perceive, report and cope with these stressors differently (Pinquart & Sörensen, 2006; Sharma, Chakrabarti, & Grover, 2016).

The literature on topics of gender generally concludes that traditional gender ideologies and men's greater earnings are the primary mechanisms through which familial dynamics are established (Coltrane, 2000; Sorenson & McLanahan, 1987; South and Spitze, 1994). In families wherein this is not the case, it has been assumed there is a more egalitarian division of responsibilities and decision-making (e.g., housework, paid work); however, results are mixed. For example, Boyle (2013) observed gender differences regarding the approach to and process of decision-making such that wife carers were more likely to use facilitative approaches to make decisions while husband carers were more likely to adopt a supervisory role in the decision-making process. However, results were mixed because they were confounded by gender, as men were more often already making the financial decisions prior to transition. Therefore, it was cases wherein men transitioned into a care-recipient role that induced the most strain because they were less confident in their partner's ability to make financial decisions. This is further complicated when power is considered.

While theories of stress and coping are common in gerontological research investigating dementia caregiving, they often fail to consider power dynamics (Dunham & Cannon, 2008). As previously noted, most caregiving research focuses on the individual caregiver in lieu of considering caregiving as a relationship between two individuals that is characterized by issues of power, autonomy, and control (Bentwich, Dickman, & Oberman, 2018; Dresser, 2001; Ekman, & Norberg, 1988). Dunham & Cannon (2008) proposed the relationship between caregiver and care-recipient is paradoxical in that the exercise of power creates an experience of powerlessness for the caregiver. They interviewed 26 female caregivers in order to understand how power and control were used in the context of a relationship. They found that there was more tension surrounding issues of power and control early on in the disease progression, and the

more power or control was utilized (often perceived as being more involved in the caregiving process), the more powerless the caregiver felt. This also facilitated reductions in autonomy on the part of the care-recipient. It is unclear how power dynamics manifest differentially based on gender of the caregiver or if this differs within the context of financial decision-making.

However, the available evidence suggests there are gender differences present that are worthy of further investigation to tailor available information and interventions for individuals living with or caring for someone with cognitive decline.

While the last several decades have seen changes in the role of women in society (e.g., Family and Medical Leave Act, Equal Pay Act, Lily Ledbetter Fair Pay Restoration Act, and a record number of women in the U.S. House of Representatives and Senate), women still vary significantly in the extent to which they feel prepared and able to navigate daily household financial management (e.g., Bisdee, Price, & Daly, 2013; Ricciardi, 2008). Gendered financial roles within households for individuals now in their 60's, 70's, and 80's are well-documented. For example, Zweig (1961) found that men controlled household finances in 70% of couples through a 'housekeeping allowance' system in which women were allotted a certain amount of money for household expenditures such as groceries. While the prevalence of such a system has decreased over time (e.g., Pahl, 1989; Vogler, Brockmann, & Wiggins, 2006), individuals now in later life, particularly women, may not have the financial ability to navigate certain financial events in the face of illness or widowhood. A study conducted by Bisdee, Price, & Daly (2013) describes gendered financial management among heterosexual couples in current older adult populations. Their analysis examined 45 older adult couples across the socioeconomic spectrum to show that women have varying emotional responses to money management. Specifically, they found women responded to financial management in later life in three primary ways. First, they

found some women accept financial inequality and dominance by their husbands, some recognize these inequalities and resent them, and some retain financial independence and power within their relationships. It was only in the latter group that women reported a longstanding history of retaining financial control and power, and they felt confident in assuming financial or fiduciary responsibilities. This has important implications regarding navigation of money later in life in the face of reduced income or paying for disability as well as women struggling to take on financial management for the first time in the face of widowhood or illness. Due to the historical gendered nature of power and money management within households, taking on financial responsibilities, perhaps for the first time in late life with the onset of a spouse's illness, presents new unexplored and unaddressed problems worthy of investigation.

### **Need for Study**

The public health significance and importance of this study is substantial. In October 2017, the National Institute on Aging (NIA) convened a workshop to examine the state of science for the cost-effective early detection of cognitive decline. An important part of its foci was the relationship between cognitive decline and financial decision-making. Earlier that same year, in May of 2017, the World Health Assembly adopted and announced a global action plan that included, for the first time, a gender sensitive approach to addressing care and quality of life among those impacted by dementias. Finally, the Global Alzheimer's and Dementia Action Alliance has proclaimed the impact of dementia on women as a global women's health, social care, and human rights challenge that must be addressed. The present study sought to address this gap and describe and understand the lived experience among women in a dementia caregiver role making new and ongoing financial decisions. This study planned to elucidate, for the first time, how financial decision-making is negotiated and executed between caregivers and care

recipients and how financial stress and income might affect these processes. Moreover, it investigated elements of financial stress, class, and gender in such processes. These findings will yield practical insights for the development of financial stress measurement tools and caregiver services to assist in coping with and managing financial stress for those of all socioeconomic echelons. In order to prepare caregivers for the financial aspects accompanying the caregiving role, a comprehensive understanding of its many facets is needed. By better understanding these phenomena, quality of care for both individuals of a care partnership may be improved through more effective educational and support programs, interventions, and policies. Moreover, findings will yield insights for aiding caregivers coping with and managing financial stress for those of all socioeconomic statuses.

### **Research Questions**

The overall focus of this research was to gather, present, and theorize caregiver perspectives of financial stress, coping, and decision-making. The aims of the current study were twofold and research questions stemmed from higher order aims. Specifically, this study explored and described experiences of financial stress from the female-identified caregivers' perspective. Key research questions were: 1) What is the nature of the underpinnings of financial stress; and, 2) how do these facets of financial stress manifest during the dyadic decision-making process?

Second, this study explored potential convergences and divergences among individuals of differing income levels (i.e., low, middle, high).

## METHODS

### **Grounded Theory Methodology**

The aim of grounded theory is to construct a theory that is grounded in the data via an iterative process between analysis and data collection to provide interpretation within a particular area of study (Glaser & Strauss 1967, 2017; Strauss, 1987; Strauss & Corbin, 1994, 1998).

Grounded in the perspectives of caregivers, this method generates and inductively tests a substantive theory designed to explain the actions of individuals (in this case, financial decision-making) in a context (coping with cognitive impairment).

The grounded theory method arises from the psychosocial theory of human action known as symbolic interactionism, wherein reality is constructed through social interaction (Blumer, 2012). Grounded theory methods are a set of flexible analytic guidelines that allow the development of inductive middle-range theories through successive levels of data analysis and conceptual development (Charmaz, 2011). One of its major strengths is that it provides tools for analyzing processes (Charmaz, 2011). This method is generally used to investigate individual and collective action, which is nicely tailored for the aim of this study to examine individual and collective processes. This method is also used to examine social and social psychological processes, such as everyday life in a given social setting, identity transformations, problem-solving processes in social groups, and responding to and coping with life changes (Thornberg & Charmaz, 2014). This nicely accentuates the aims of this study regarding the identity/role transitions and decision-making processes within the context of financial management and stress. Therefore, this method is appropriate to address the research questions. This study examines how

caregivers perceive dyadic financial decision-making, the conditions under which such decision-making takes place (the influence of contextual elements such as financial strain), and the consequences of the decision-making process for the caregiver and her/his family member with dementia. These elements and their interrelationships are the essential components of substantive theories on complex social processes generated by the grounded theory method (Strauss, 1987).

More specifically, a *constructivist* grounded theory approach (Bryant, 2009; Charmaz, 2008) rooted in pragmatism and relativist epistemology was employed. Unlike more traditional grounded theory approaches, a constructivist approach addresses previous criticisms surrounding notions of objectivity. A constructivist approach adopts grounded theory guidelines as tools but does not subscribe to the objective assumptions, but rather assumes that neither data nor theories are discovered but are co-constructed by the researcher(s) and caregivers together. It further assumes this process of construction is influenced by the researchers' sociocultural setting, academic training, and personal worldview (see this author's subjectivities statement in Appendix A; Charmaz 2008). A constructivist approach assumes an obdurate reality while simultaneously assuming multiple realities and multiple perspectives on these realities (Bryant & Charmaz, 2010; Charmaz, 2008).

### **Recruitment & Caregivers**

Caregivers were eligible if they: 1) self-identified as the primary caregiver for the care recipient; 2) provided assistance with financial management and decision-making; 3) provided assistance with at least 2 instrumental activities of daily living (IADLs) for the care recipient; 4) passed the Short Portable Mental Status Questionnaire (SPMSQ; Pfeiffer, 1975) with no more than three errors; 4) scored between 2 and 20 on the Quick Dementia Rating System (QDRS; Galvin, 2015), and 5) were fluent in English. Caregivers were ineligible if they: 1) presented



with severe psychiatric illness such as schizophrenia or bipolar disorder; or 2) endorsed suicidal ideation. A formal diagnosis was not required in order to maximize recruitment among caregivers facing issues regarding access, particularly among low income/rural caregivers.

While there are no specific rules when determining appropriate sample size in qualitative research, Creswell (2014) recommends recruiting five to 25 individuals. Patton (1990) suggests that qualitative sample size is best determined by the time allotted, resources available, and study objectives. As a result, this study attempted to recruit 18 dyads. Purposive sampling was employed in order to recruit a racially diverse sample distributed across three levels of income (low, middle, and high) using the Pew Research Center income calculator. For purposes of feasibility, recruitment focused solely on female-identified spousal caregivers only. Purposive and theoretical sampling occurred in tandem with data analysis as part of an iterative process. Therefore, analysis began upon initial collection of data and informed subsequent recruitment. Consistent with this methodological approach, the target sample size was an initial estimate that was subject to change as it was informed by the analytic procedure (see Analysis section for detailing of the simultaneous processes of data collection, coding, comparison, and analysis).

## **Screening Measures**

### **Demographics**

During the screening process, basic demographic information was collected. This included age, race/ethnicity, state, rural/urban location determined by RUCA codes, level of education, estimated objective income, level of financial stress, and partnership length.

**The Quick Dementia Rating Scale.** The Quick Dementia Rating Scale (QDRS; Galvin 2015) is a quick dementia staging tool that can be administered over the phone that measures ten different domains of cognitive and behavioral functioning in dementia. It was administered to the

Caregiver as an informant to determine level of care recipient impairment. The total score is summed for a global score, then two subdomains are calculated by summing the respective domains. This yields a cognitive (questions 1, 2, 3, and 8) and behavioral (questions 4, 5, 6, 7, 9, and 10) score. Higher scores indicated greater impairment. It has demonstrated strong validity and reliability (Cronbach  $\alpha$ : 0.86–0.93) with scores highly positively correlated with the CDR (Ps < .001; Galvin, 2015).

**The Clinical Dementia Rating Scale.** The Clinical Dementia Rating Scale (CDR; Morris, 1997) is considered the gold standard of assessment of global functioning in Alzheimer’s disease. It was administered to the Caregiver as an informant to determine level of care recipient impairment. It uses a 5-point scale for six domains of cognitive and functional performance applicable to Alzheimer disease and related dementias. These domains include: Memory, Orientation, Judgment & Problem Solving, Community Affairs, Home & Hobbies, and Personal Care.

**Perceived Income Adequacy.** Perceived income inadequacy was measured by four categories ranging from 1 = *not easy at all* to 4 = *very easy* based on a response to the question “How easy is it for you to pay for the very basics like food, housing, medical care, and heating?” (Sun et al., 2009).

## **Recruitment**

Caregivers were recruited primarily through referral from community adult day care facilities in Tuscaloosa, Alabama and Durham, North Carolina. The study was also advertised via IRB-approved flyers. Caregivers were also recruited through rural and urban community stakeholders who served as members of project SOAR (Sharing Opinions and Advice about Research in the Deep South; PCORI contract #1097, RS Allen, PI).

Caregivers were first screened to ensure eligibility (see Appendix B). On the day of the interview, caregivers completed the appropriate consent forms, were administered the Clinical Dementia Rating scale (CDR; Morris, 1997), and completed the semi-structured interview (adapted from Samsi & Manthorpe, 2013; see Appendix A). Interviews were audio recorded, transcribed for analysis using www.rev.com, and deidentified for coding. Caregivers were compensated \$10.00 per person (i.e, \$20.00 per dyad). Additionally, Caregivers received the *Complete Eldercare Planner, Revised and Updated Edition: Where to Start, Which Questions to Ask, and How to Find Help* by Joy Loverde, *Who Will Take Care of Me When I'm Old* by Joy Loverde.

As this writer reflected on interview experiences during the memoing process, ethical considerations arose due to discomfort in asking questions about future financial end-of-life decision making. Memos noted great discomfort in asking questions in a way that might highlight potential risks of not engaging in these decisions. Moreover, noted throughout memos was discomfort regarding the ability to intervene with some of these caregivers given their verbalized desire to engage in planning while also noting cognitive-behavioral barriers. As a result, this writer attempted to balance desire to achieve research goals and ethical questions about focusing caregivers' attention on an issue they may be actively avoiding by not probing too deeply. Unexpectedly, this writer noted integrated healthcare systems, that might be best situated to aid these individuals in meeting their goals, do not necessarily exist. If they did, and the writer had knowledge of them, she would have promptly made referrals and provided education of their existence. In lieu of this, the interviewer refrained from asking questions too in-depth about avoidance of financial planning to reduce stress, and rather provided a packet of

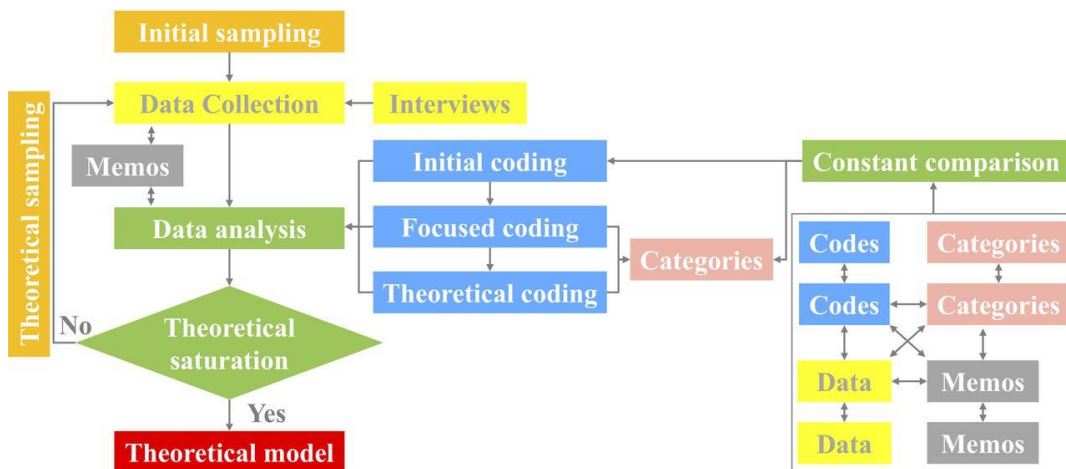
local support resources and education about therapy and how it might possibly aid in death acceptance and behavioral activation to increase financial planning and reduce financial stress.

**Analytic Strategy**

As is customary in grounded theory methodology, the first piece of data initiated a continuous iterative process wherein data collection and data analysis occurred in tandem (Glaser & Strauss, 1967). The analytic process employed constant comparison of data wherein differences and similarities in the caregivers’ experiences enriched and gave rise to theory (Glaser & Strauss, 1967). Each interview was first transcribed then analyzed according to the coding paradigm outlined by Charmaz (2008; Thornberg & Charmaz, 2014; see Figure 1), in order to describe lived experience of financial stress and decision-making.

**Figure 1**

*A visual depiction of Grounded Theory.*



**Initial Coding**

Initial coding focused on labelling segments of data and then categorizing and summarizing said segments. Coding began upon the collection of the first piece of data following the transcription of the first interview. Coding allowed researchers to interact with and explore

the data while asking analytical questions. This facilitated a subsequent defining process during which researchers used the data to determine codes. Constructivist grounded theory consists of two coding phases: initial (also known as open) coding and focused (also known as selective) coding (Charmaz, 2008). Coding is not a linear process and is sensitive to theoretical possibilities, therefore, researchers move back and forth between phases of coding. However, more initial coding is often conducted in the beginning (Charmaz, 2000, 2008; Charmaz & Smith, 2003). Researchers drew from questions proposed by Thornberg & Charmaz (2014) during the initial coding phase:

a) What is this data a study of?; b) What category does this incident indicate?; c) What is actually happening in the data?; d) What is the Caregiver's main concern?; e) What do the actions and statements in the data take for granted?; f) What process(es) is at issue here? How can I define it?; g) How does this process develop?; h) How does the Caregiver(s) act and profess to think and feel while involved in this process?; i) What might his or her observed behavior indicate? and; j) When, why, and how does the process change and what are its consequences. (p. 155-156).

Researchers used coding in a flexible and sensitive way to label codes with gerunds such as 'anticipating costs' or 'planning.' This was done in a line by line and incident by incident fashion. Constructed codes were understood as provisional and subject to revision and refinement at regular meetings as agreed upon by the coding team. During the coding process, a constant comparative method was employed where data was compared to data at various level of analysis (e.g., data with data, code with code, and data with code) across phase in order to find convergences and divergences (Glaser & Strauss, 1967). This method facilitated categorization of initial codes such that more elaborate codes emerged.

## **Focused Coding**

The second phase employed was focused coding. These focused codes were used to sift through large amounts of data in order to identify a core code category, which is the most frequent and central (i.e., related to the most other codes). This further guided data gathering and coding. This traditional view has been criticized for being too restrictive, and more sensitive and flexible approaches have been suggested, particularly within a constructivist grounded theory framework (Charmaz, 2008; Thornberg & Charmaz, 2014). Given this study was conducted within the constructivist grounded theory framework, it employed a more contemporary approach that yielded two core code categories and two contextual coding categories. More contemporary approaches to focused coding allows for more than one significant or frequent initial code to conduct further work.

The researchers explored and decided which codes best captured what was occurring in the data and raised these codes up to conceptual categories and assessed relationships among said categories (Charmaz, 2003; 2006). Thornberg and Charmaz (2014)'s suggested list of various comparisons was utilized:

a) comparing and grouping codes; b) comparing codes with emerging categories; c) comparing different incidents (e.g., social situations, actions, social processes, or interaction patterns); d) comparing data from the same or similar phenomenon, action or process in different situations and contexts, comparing different people (their beliefs, situations, actions, accounts, or experiences); e) comparing data from the same individuals at different points in time; f) comparing specific data with the criteria for the category; g) comparing categories in the analysis with other categories and; h) a third coding strategy will be employed—theoretical coding. (p. 158-159).

## **Theoretical Coding**

Given the state of qualitative research in the area of grounded theory, this method included substantive then theoretical coding strategies. While initial and focused coding generate data-driven and empirical codes and categories, theoretical coding identifies underlying logics and mechanisms that are described in pre-existing theories. Glaser (2005) argued that studying many theories enables researchers to identify theoretical codes embedded in the data. While he outlined a list of his own theoretical codes for researchers to use (Glaser 1978), Charmaz (2006) criticized using this list for being arbitrary and vague and later, Thornberg & Charmaz, (2012) encouraged researchers to investigate various relevant theories of their choosing for coding purposes. However, it was emphasized that adopting and applying theoretical codes, again, introduces the risk of preconceiving and contaminating analysis and should therefore remain “theoretically agnostic” and critical of applying any given theories to the data.

## **Theoretical Saturation**

As coding continued, researchers remained mindful and diligent as they used the analytic process to inform recruitment, sampling, and data collection. Data collection was completed once theoretical saturation, or when the data no longer introduced new theoretical insights or codes, was achieved. Some inquiries used to guide this process as outlined by Thornberg & Charmaz (2014) included: “a) Are there any gaps in the grounded theory or in its categories?; b) are there any vague or underdeveloped definitions?; c) are we missing some data?, and; d) are the findings coherent? (p. 162). Once eight consecutive interviews were coded that return no new codes by any members, a meeting among coders (Keisha Carden, Dr. Rebecca Allen, and an external research collaborator) was held to discuss the saturation criteria. Coders agreed saturation had been met following completion of the eighteenth transcript.

## **Reliability and Validity**

Best standards of qualitative methodology that support validity are rigor, trustworthiness, credibility, and believability as well as an awareness and acknowledgement of subjectivity (Russell & Gregory, 2003; See Table 2 for Validity Matrix). In this study, we maximized trustworthiness of our findings by engaging in reflexive practices to remain aware of subjectivity and coder biases (i.e., subjectivity statements and memo writing; See Appendix A). This study also utilized investigator triangulation whereby a three-member analysis team independently analyzed interview data transcripts for themes. This helped investigators maintain awareness of biases in order to enhance interpretation of the data (Thorpe & Holt, 2007). Each transcript was read and analyzed independently. Analysis and emergent categories and themes were discussed at regularly scheduled research meetings, wherein refinements were considered by the coding team. Throughout coding, constant comparative methods were employed in order to achieve recognition of similarities and differences until consensus was reached. Reflexive practice was maintained through detailed memos, which were kept throughout the process in an effort toward transparency and visibility of analytic decision-making (Bradley, Curry, & Kelly, 2007).



## RESULTS

Interviews were conducted at the caregivers' residences (77%) or over the phone (17%) depending on the Caregiver's preference for location. One interview was conducted at the University of Alabama's Research Institute on Aging (6%). All caregivers identified themselves as primary decision-makers for their family member with dementia. Caregivers were all female-identified spouses with a mean age of 67.94. Twelve were non-Hispanic White and six were non-Hispanic Black; two identified as cis-gender and queer. The overall mean income was \$89,080.00 with a standard deviation of \$85,069.37. Caregivers' reported income levels and geographic location were used to compute income level based on Pew Research Center's income calculator and were evenly distributed across low, middle, and high income levels. Mean incomes were \$24,573 (SD = 8,257.13), 61,000 (SD = 21,307.28), and \$181,666.67 (SD = 88,637.84), respectively. Descriptive statistics and demographic data are reported in Table 1.

**Table 1**  
*Demographics N = 18*

Sample Characteristics	Income Level			
	Low n = 6 M (SD)	Middle n = 6 M (SD)	High n = 6 M (SD)	Across Income Level M (SD)
<b>Demographics</b>				
<b>Age</b>	67.50 (11.73)	70.83 (6.37)	65.50 (1.52)	67.94 (7.63)
<b>Race (1 = NHW)</b>	67% (n = 4)	67% (n = 4)	83% (n = 5)	72% (n = 13)
<b>State (1 = AL)</b>	50% (n = 3)	83% (n = 5)	67% (n = 4)	67% (n = 12)
<b>Rural/Urban (1 = Rural)</b>	67% (n = 4)	50% (n = 3)	33% (n = 2)	50% (n = 9)
<b>Education</b>	3.5 (1.76)	4.17 (1.83)	5.33 (1.97)	4.33 (1.91)
<b>Income</b>	24,573.33 (8,257.13)	61,000 (21,307.28)	181,666.67 (88,637.84)	89,080.00 (85,069.37)

<b>Financial Stress</b>	2.33 (.526)	2.00 (.89)	2.17 (.98)	2.17 (.79)
<b>Income Adeq</b>	2.17 (1.47)	3.5 (.548)	3.33 (.82)	3.00 (1.14)
<b>Marriage Length</b>	39.00 (20.21)	47.83 (8.68)	31.83 (10.13)	39.56 (14.76)
<b>Total ADL/iADL</b>	8.83 (2.23)	9.33 (2.94)	9.17 (3.93)	9.11 (2.56)
<b>QDRS</b>	12.83 (5.14)	10.17 (3.33)	11.00 (5.52)	11.33 (4.62)
<b>CDR</b>	1.25 (.82)	.92 (.20)	1.17 (.68)	1.11 (.61)

*Note. Education:* 1 = Less than High School degree, 2 = High School Degree, 3 = Some college, 4 = Associates Degree, 5 = Bachelor's Degree, 6 = Master's Degree, 7 = Greater than Master's Level; *Financial Stress:* 1 = Not at all, 2 = Somewhat, 3 = Very; *SES Strata:* 1 = Low, 2 = Middle, 3 = High; *Income Adequacy:* 1 = Not Easy At All, 2 = Somewhat Easy, 3 = Mostly Easy, 4 = Very Easy; *QDRS = Quick Dementia Rating Scale; CDR = Clinical Dementia Rating Scale*

As reported income adequacy increased, reported financial stress decreased,  $r = -.526, p < 0.05$ . Notably, as age increased, so did reported income adequacy,  $r = .603, p < 0.05$ . All bivariate correlations can be found in Table 3. QDRS scores ranged from 3.5 to 20 with a mean of 11.33 ( $SD = 4.62$ ). CDR scores ranged from .5 to 2 with a mean of 1.11 ( $SD = 0.61$ ). In other words, eight PWDs had mild cognitive impairment, and eight had moderate cognitive impairment as reported by the caregivers.

**Table 2.**  
*Bivariate Correlations*

	Age	Race	State	Rural/ Urban	Education	Financial Stress	Income	Income Adeq	SES Strata	Total ADL	QDRS
Age	---										
Race	-.146	---									
State	.419	.088	---								
Rural/ Urban	-.037	-.124	-.236	---							
Education	-.043	.156	-.381	.599**	---						
Financial Stress	-.303	-.135	-.309	-.073	.000	---					
Income	-.132	-.130	-.224	.488	.596**	-.142	---				
Income Adeq	.603**	.000	.213	.101	.162	-.526*	.409	---			
SES Strata	-.110	-.152	-.144	.272	.403	-.089	.776	.431	---		
Total ADL/iADL	-.267	.541	.077	.145	.137	.095	.061	-.164	.089	---	
QDRS	-.021	.064	.079	.062	-.083	.203	.011	-.286	-.167	.539*	---
CDR	-.170	-.012	.07	.188	.118	.205	.173	-.298	-.058	.534*	.887*

*Note. ADL = Activities of Daily Living, iADL = Instrumental Activities of Daily Living, QDRS = Quick Dementia Rating Scale, CDR = Clinical Dementia Rating; \* = Correlation is significant at the 0.05 level (2-tailed), \*\* = Correlation is significant at the 0.01 level (2-tailed).*

## **Grounded Theory Overview and Introduction**

**Financial Stress and Decision-Making.** The relationship between financial stress and decision-making appeared to be complex and nuanced. Caregivers’ reports of their lived experience concerning finances emerged in domains of cognition, behavior, emotion, relationships, social networks, and economics which in turn impacted decision-making processes (see Table 3). More specifically, where relational, social, and economic factors were concerned, caregivers elaborated on how issues of social class and access to resources concerning power, knowledge and information, and services impact their financial decisions particularly regarding their caregiving role. Overall, while caregivers had considered financial planning for the immediate time period following the death of their loved one (e.g., for funeral arrangements), many had not planned for health-related or care-related costs in the interim.

**Avoidance.** One theme that emerged throughout each domain of financial orientation was avoidance of making financial decisions related to end-of-life care. While many caregivers acknowledged the likelihood of their loved ones’ decline, avoidant coping and disengagement manifested across identified themes (See Table 3).

**Table 3**  
*Avoidant Coping and Disengagement in Decision-Making*

<b>Avoidance and Disengagement</b>	
<b>Cited Reason</b>	<b>Caregiver Quote</b>
Lack of information	But I asked her what the monthly cost is, and she said you really don't know because they don't have a set amount. Like, you know, you know that this level of care, but did you have to hire sitters or you know, if you have to hire somebody to manage their medication, that's an additional cost. So it's all of these sort of, you know cafeteria costs and you've got to add that. So it was very hard, very hard. I

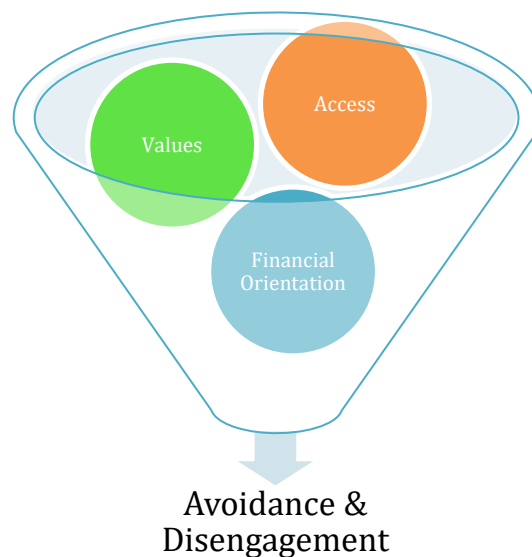
	think in a more... I don't want to say in an unsophisticated Market, but an unsophisticated Market. (1011)
Low self-efficacy and uncertainty due to lack of knowledge (despite consultation with professionals in various fields)	It's stressful and it's such a huge knowledge gap for me. I don't even know what I don't know or how to go about knowing it. I pay the bills and stuff, but none of that other financial decision-making. (1004)
High self-efficacy regarding future reactive decisions (e.g., I'll cross that bridge when I get there)	I do see some deterioration in language ability, but nothing that I have to act on right now. I'll do it when I absolutely have to. I'm not really worried about it, we have enough money and assets for when we need it. (1018)
Low perceived control	The biggest problem to me is the uncertainty and the unpredictability of it. I can't anticipate it. It's like a rollercoaster. (1016)
High perceived control	Just an update on how he's doing and then we once discussed how much money it might take if he were in a home, and it seemed like I had enough money to take care of that then, so I don't know. I don't know how much. I think the estimate they gave me was a little low, but it hasn't yet been an issue that we've had to address seriously. We can do that when necessary. (1018)
Resources	And so, um, I think, you know, at some point, I'm aware that- 'cause if you were paying \$150,000.00 a year for care, and if you were in a nursing home, (laughs) a few years, you could go through a heck of a lot of resources with that. (1003)
Low level of resources	And oh my goodness, the finances is such a huge piece of it. I can certainly see how that's a slippery slope. And I mean, we don't go around telling this to everybody. But you know, then you don't want to ever be in the situation where the family is putting pressure on somebody to go ahead and [withdraw food and water] because you're running out of money or your finances. (1011)
Values and preferences to die at home	And so no, I'm not planning...But I'm planning on him staying here as long as you know, because that was his desire. (1015)
Death anxiety	And do not feel comfortable at all talking about scary stuff or reality or...And [PWD] is not really able to. (1011)

Caregivers unanimously reported avoidance of engagement in financial planning for a number of reasons which included overwhelming uncertainty or lack of knowledge and information despite, in some cases, consultation with financial planners, healthcare workers, and assisted living facilities, skilled nursing facilities, and retirement communities. Some highlighted a “one day at a time” and “we’ll cross that bridge when we get there” mentality and attributed

this to their high levels of self-efficacy in financial decision-making. Others acknowledged the possibility of decline in functioning to the point that care-demands might outweigh caregivers' care-related abilities. Caregivers largely reported that their values concerning quality of end-of-life experience and control over that process on behalf of their loved one were most important. All caregivers expressed preference (to varying degrees) to keep their loved one at home.

It seemed caregivers had considered decision-making in location of care and possible placement to be largely simplistic and dichotomous—either keep their partner at home or pursue facility placement. There was little to no verbalization of consideration or discussion of nuanced solutions such as hiring in home care providers if the need arose. This was the case for all caregivers—even those who were caring for someone in the more moderate to severe stages with anticipated further decline in functioning. This held true even in cases in which the Caregiver acknowledged declining abilities to meet care demands (e.g., physical aid in mobility and transfer, ability to provide care and continue to work).

**Figure 2.**  
*Caregiver Process of Avoidance & Disengagement*



While this finding was robust, the underlying reported thought processes varied by income. Specifically, individuals who reported lower income and access shared that more fiscally demanding solutions (e.g., assisted living) were historically never an option and their communities “care for their own”. Although these individuals had not engaged in care- or financial- planning discussions with family or friends, there was a reported assumption that these individuals would “make it work” and “pitch in” as needed. These individuals highlighted a history of financial strain to which they appeared to have adapted. As a result, future decline in which care demands surpass the individual’s care-related capacity was not appraised as a threat that warranted planning financially or having discussions now about how they would meet this need in the future.

Individuals in the high SES category also endorsed high levels of avoidance for financial planning for end-of-life. However, these individuals described a history of perceived financial well-being and little financial threat. Therefore, they reported they did not believe they needed to plan financially for future care-related costs in the face of decline. They believed they would have the means to do whatever was necessary (such as to meet care demands and their partner at home). Interestingly, when asked to recount past instances of making care-related financial decisions, caregivers in low and high income groups consistently reported they wished they had planned sooner and would advise others in their situation to do this and “learn from others’ mistakes.”

Individuals in the middle-income tier seemed more likely to have attempted planning for future care-related costs. However, these individuals ultimately engaged in the same avoidant coping that low- and high-income caregivers endorsed. Middle-income caregivers had not made plans to pay for care costs because as much as they had attempted, they were not able to obtain

the information they needed. Several caregivers described reaching out to possible facilities to inquire about care options, and no one could provide clear prices. Others reported they were told they may need to “spend down,” liquidate assets, and sell property in order to pursue some of these potential plans. This triggered considerations for the caregivers’ own potential care needs related to their end-of-life experience. These caregivers reported overwhelming uncertainty about having enough resources for both their loved one’s care and their own. Caregivers shared that in combination, this uncertainty related to costs and the perception that trying to learn how much cost to plan for was “paralyzing”. This “paralysis” led to overwhelming and seemingly “unnecessary” stress. One caregiver described feeling they were “damned if [they did] and damned if [they didn’t]”.

**Table 4.**  
*Categories and Themes*

Categories	Themes and Subthemes	Description
Financial Orientation	<ul style="list-style-type: none"> <li>• Role <ul style="list-style-type: none"> <li>○ Independent</li> <li>○ Shared</li> <li>○ Historical experience</li> </ul> </li> <li>• Style <ul style="list-style-type: none"> <li>○ Proactive</li> <li>○ Reactive</li> </ul> </li> <li>• Approach <ul style="list-style-type: none"> <li>○ Emotion-focused/Affective</li> <li>○ Problem-focused/Analytical</li> </ul> </li> <li>• Motivation</li> <li>• Management <ul style="list-style-type: none"> <li>○ Daily Decisions</li> <li>○ Budgeting</li> </ul> </li> <li>• Capacity <ul style="list-style-type: none"> <li>○ Perceived control</li> <li>○ Self-efficacy</li> <li>○ Income Adequacy</li> <li>○ Support Seeking</li> </ul> </li> <li>• Resources <ul style="list-style-type: none"> <li>○ Financial Literacy</li> <li>○ Income</li> </ul> </li> </ul>	The cognitive, emotional, behavioral, relational, social, and economic aspects of financial behavior in the context of values related to current and future care, quality-of-life, and quality-of-death.

	<ul style="list-style-type: none"> <li>○ Support</li> <li>● Planning <ul style="list-style-type: none"> <li>○ Preparedness</li> <li>○ Anticipating Costs</li> </ul> </li> </ul>	
Access	<ul style="list-style-type: none"> <li>● Power (Navigation of Policies and Procedures)</li> <li>● Resources (Social Benefits/Healthcare)</li> <li>● Information (Health literacy/Understanding dementia process)</li> </ul>	Refers to ability to obtain, examine, or retrieve power, resources, or information. Discussed within the context of navigating healthcare, social, and legal policies and procedures, obtaining specific tangible social and healthcare benefits, and level of health literacy and knowledge of dementia process.
Values	<ul style="list-style-type: none"> <li>● Effective/Exemplary caregiving</li> <li>● EOL planning</li> </ul>	The degree of importance of beliefs about behaviors and ways of living. This is discussed regarding current and future care, quality-of-life, and quality-of-death for both the PWD and Care Partner.

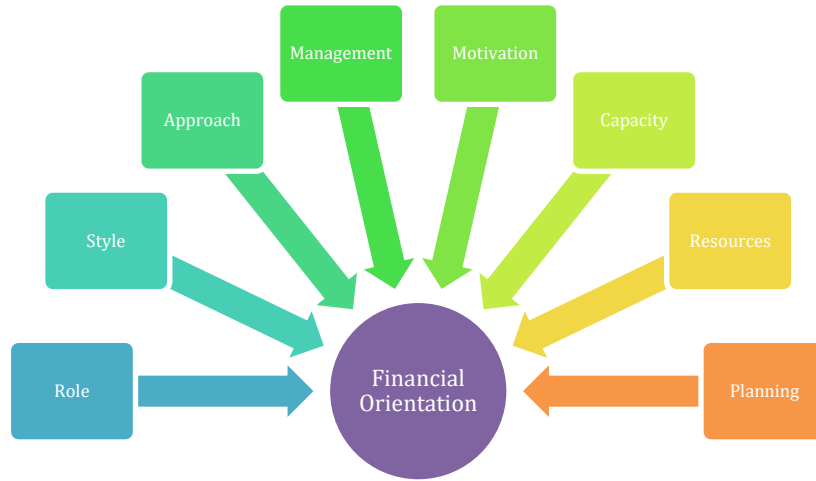
### Categories and Themes

Table 4 includes a brief description of the major categories, themes, and processes. Three primary categories emerged from the data: *Financial Orientation*, *Values*, and *Access* (see **Figure 4**). These three categories were identified by the coding team and confirmed over time.

**Financial Orientation.** This conceptual category included numerous affective, cognitive, behavioral, relational, social, and economic dispositional lenses through which they appraised potential financial stressors. These included decision-making role, style, approach, management, motivation, capacity, resources, and planning (see **Figure 3**).



**Figure 3**  
*Financial Orientation*



This brings to light many factors underpinning financial stress beyond those typically examined in caregiving research such as income adequacy. For example, in this study, 79% (n = 14) of caregivers reported perceived income adequacy (i.e., mostly easy or very easy); however, 79% (n = 14) of caregivers also reported caregiving was financially stressful. Caregivers reported numerous factors contributing to their financial stress levels. These included: 1) necessity to plan for care (both their loved one's and their own), 2) end-of-life-related costs, 3) budgeting for possible unknown events, 4) not feeling familiar with what resources were available to aid in financial planning or decision-making, 5) inconsistent information, 6) lack of interest or desire or perceived utility regarding financial planning and decision-making, and 7) uncertainty of the future. Overall, caregivers reported a significant degree of avoidance of financial decision-making, particularly if the decision triggered thoughts and emotions related to the decline or death of their loved one or themselves. This held true across income level, and decision-making style and approach. In fact, caregivers reported that when decisions arose at the intersection of finances and end-of-life, they were more likely to engage in avoidance and be more reactive in

their decision-making. Among individuals who reported income adequacy, their priority in financial decision making was ensuring and enhancing safety and quality of life of their loved one, but only during a small window of time. Caregivers were avoidant of making financial decisions congruent with this value in the context of future planning and end of life.

***Decision-Making Role.*** Caregivers experience of their decision-making role was discussed in terms of a continuum of responsibility. This ranged from being completely independent in the financial decision making to including the care-recipient in the discussion and execution of financial decisions. Caregivers highlighted the importance of their historical role in making dyadic financial decisions with and for the PWD. Surprisingly, a significant portion (89%, n=16) reported having always assumed the primary financial decision-making role and attempting to maintain and extend that primary decision-making role. For example, one Caregiver explained that while she and her partner had always discussed “big” purchases together, she always paid bills for regular necessities:

But, you know, you got to manage money, right? And well, I managed it all because you see he's really not, he's never done the financials as far as that. You know, we always talked over about big purchases but as far as him paying the bills, I've always done that. (1000)

While her husband no longer retained the capacity to engage in cognitively demanding discussions about larger financial decisions, she explained she felt she had been making decisions with him for so long that she knew what his values were and what he would want. She shared she tried her best to honor that out of love and respect for his personhood.

This phenomenon held true even in cases in which caregivers reported their partners either generated the larger portion of income or made decisions about investments and larger assets. Many caregivers explained they had always maintained their own separate accounts and

that they were more responsible with finances compared to their partners. For example, one Caregiver shared:

He and I, when we first married... He tried really hard to combine our incomes and thought he should do it. But I wasn't going for that. We had a joint bank account for a while, and he constantly wrote more than we had. He um, was interested in that um... When I first noticed that wasn't working we were something like \$300, maybe overdrawn. So then we split them. I managed my money then. (1002)

Many caregivers who described having always made the financial decisions reported this made the transition into the caregiver role easier because they felt confident in their abilities to manage new financial circumstances and demands:

That made the transition easier. Because I knew what was going on. I'm saying well, I've had friends let their husbands handle all the financials and they don't really know what to do and it is damaging to them and its more stress on them if they don't know how to do it. I'm just doing it like I always have (1000).

Some individuals shared they had assumed the primary financial decision-making role because it became a necessity prior to the beginning of the cognitive impairment.

Others reported it was necessary because of cognitive decline. A significant portion of caregivers reported dyadic financial decision-making was often the domain in which they noticed cognitive changes. However, for those caregivers who noted historically maintaining separate accounts, this delayed the detection of cognitive decline.

***Decision-Making Approach.*** Caregivers described their process of decision-making as falling into one of two primary approaches. They described focusing on problem solving or they focused on emotional regulation and quality-of-life. Caregivers who endorsed a more problem-focused process described more analytical thinking. Caregivers who endorsed a primary focus on emotional or quality-of-life outcomes endorsed more affective thinking. Many caregivers described their partners had a pattern of making poor financial choices prior to cognitive impairment and willingly allowed the caregiver to handle financial decisions. These caregivers

shared this was decided on primarily together as it was the best problem-solving solution. For example:

He spent money like water... And so, um, all the money went in my checking account. Once we got married, I started handling the money. I didn't so much handle his money. He could spend whatever he wanted to. It was his money. (1006)

One caregiver shared that cognitive impairment had made it easier to engage in decision-making as their partner's cognition declined because they were able to make decisions independently:

Interviewer: Are there any decisions that he helps make? Or he's involved in at this time?

Care Partner: Not really. [The cognitive decline] has made it much easier to make the decisions. I just take care of it. Some people I know say their husbands get more obsessive, but not PWD, he just went with it and doesn't ask about it. (1007)

For other caregivers, however, their priority was not necessarily oriented to problem-solving, but emphasized the emotional importance of enhancing their partner's involvement in making decisions even when this increased caregiver distress. Even among caregivers of individuals with more moderate cognitive impairment, attempting to maintain the PWD's involvement in decision-making was a priority out of respect. When asked about what decisions were still shared, one respondent said:

Oh I ask his opinion about everything. That keeps him involved (1006)

Another shared:

And he we- and I still, even now. He's, he's in that moderate stage. And I still, ...I'll say "You got the money...go ahead and take care of it." Like that. I still just include him. And he may not understand a lot of times, and sometimes he does. And, but I just still give him that respect. (1009)

Another responded:

Interviewer: Do you still talk with him about financial decisions?

Caregiver: Oh, yeah, we would talk about it. I wouldn't leave him out of it. And I would let him go with us to purchase things, you know. (1001)

A fourth shared:

And I, you know, there- I can't change the course of the disease, but I can be as kind and as inclusive as I can. And, yeah, it takes a little extra for me to do that, but I feel like I need to do it that way, I want to do it that way. (1004)

In cases when there was a difference of opinion or decisional conflict, it was common for caregivers to cite using their previous knowledge of and experience in shared decision-making with their spouse in order to inform decisions. For example:

And so, one of the things that's been difficult is he keeps wanting to change beneficiaries on stuff, his stuff. But, I mean, we have combined money, but he has IRA's, and stuff like that. I try to keep him involved and let him come with me to talk to the financial advisors, but it's getting to the point where he's wanted to change so many of the things we had already decided on together. I know he wouldn't really want that, so I haven't been initiating those kinds of discussions as much as I used to. It's a balance. (1006)

They also cited other aspects of their decision-making process that frequently integrated prayer, meditation, reflection, or consultation with a financial professional. For example:

Uh, I guess with major decisions I go to my financial uh, advisor. And I guess first and foremost I pray about it (laughs). I pray about it, uh, first. And uh, and I don't make any hasty decisions in time, I have to, like my husband said, well he would say, uh... uh... he would say, sleep on it. He would say, let me cook it for a little while. (1009)

Some described experiencing distress when making financial decisions and a preference to relinquish financial decision-making responsibility as much as possible:

It's stressful and it's such a huge knowledge gap for me. I don't even know what I don't know or how to go about knowing it. I pay the bills and stuff, but none of that financial decision-making stuff. (1004)

Others who felt they had no choice in assuming financial responsibilities, either before or after the cognitive impairment, explained they were happy to relinquish decision-making to a trusted family member where possible:

Well I'm getting better about it, you know I just have to interact. But I can't stand doing that stuff. I let my son do most of it for me. He's tech savvy. You know, I decide whose decision is this to make...[My son] has set up automatic draft, and he pays the bills regularly and lets me know how much money I have for whatever else I want...like if I want to go into town or send money to my grandkids. Some of it is new for me. And he has me buying on a um, credit card. Like groceries and medicines and little things like that, you know. Well, usually when he looks it up on the computer, it tells me how much... He says, oh! This is a little heavy, mother. [Laughs]. Really? But I appreciate it... Honey, if anybody would take the responsibility, I'd give it to them (1002).

*Decision-Making Style.* Caregivers described their decision-making experience as dispositional and endorsed either attempting to eliminate problems and stress in advance (i.e., proactive) or waiting until an event occurs to respond (i.e., reactive). Interestingly, caregivers described historically having a proactive style in which they attempted to decrease the likelihood of having financial issues later. These included behaviors such as budgeting, consulting with financial planners, and saving. However, when it came to their role as a caregiver and considering upcoming care-related expenses, they described a more reactive style. Many caregivers said things like, “we’ll cross that bridge when we get there” or “I have thought about [planning for future care], but I don’t know if I need to right now.” For example, one Caregiver proclaimed:

Well we're not at that point yet. He can still shower himself and bathe. Not as often as I'd like for him to. But he doesn't stink. So as long as he doesn't stink, and his clothes are not obviously dirty, I just kind of, you know, let him do what he wants to. So I haven't even really thought about what that would look like. I don't know how to even figure that out. I guess I would ask my son. (1002)

When one Caregiver was asked about any tips she would give other caregivers early in the transition process, she reflected on a few things she wished she had done differently:

To prepare yourself for a different change every day. To find places, long term, that will assist your needs as well as your loved one's needs. Be sure that they are safe environments and, if you can, put away something financially for hard times, definitely do that. (1010)

Overall, caregivers shared they wished they had planned more in advance and been more proactive about their partners future care needs but had found themselves frequently in positions where their only option was to engage in reactive decision-making. This was reportedly more stressful than if they had planned.

***Financial planning.*** Caregivers also described their experiences of making financial plans. This section explores different types of planning in which Caregivers engaged along a continuum. Many Caregivers reported having been financially planful over the course of their lives, **but not one Caregiver had endorsed making financial plans about future healthcare for their partner or for themselves yet.** However, most caregivers reported they believed they possessed knowledge and skills to engage in necessary financial planning, particularly as it related to future healthcare, quality of life, and leaving money or assets for children.

Um, planning is necessary and one quote that uh, our old uh, our former pastor, he's our Pastor Emeritus, uh, said and he said, "If you fail to plan, you plan to fail." (1009)

Although caregivers largely reported valuing financial planning, there was variability in terms of what was meant by "planning." Caregivers ranged in types of plans they made and included saving for unexpected events, building credit, and purchasing various healthcare and retirement policies. For many, planning was equivalent with saving money for unknown future circumstances. For example:

Um, just trying to build as much, um, income as possible, trying to level everything off. I still have a little bit of debt to take care of, um, that wasn't, um, absolved. But, um, I'm on the road to getting all that done, and, um, making a different type of income is a little bit different- ah, than what I was making before, so. But our expenses are considerably less, so I don't have all the expenses that I had before, so. (1012)

Others reported they had prioritized preparation of legal decision-making documents:

So in some ways, it does allow for some planning. And I think we've done, you know a good job of that. Like depending on what kind of account it is his kids, you know have Financial Power of attorney and you know, we've already taken those steps. (1009)

Many (n = 6) shared they were not sure how to move forward with planning because they felt they had missed the window of opportunity to discuss with their partners their wishes:

...It's too late to have that conversation and make a decision together. But so far, he's, you know, all right. Now, he may very well have another brain bleed, and if he does, our neurologist said, she didn't think he would survive it. (1004)

Some felt avoidant of engaging in planning because of feelings of discomfort, fear, and uncertainty:

And do not feel comfortable at all talking about scary stuff or reality or...And [PWD] is not really able to...We need to have that conversation or certainly guide it. I feel uncomfortable, you know being the one who says okay so here's the deal. And unfortunately the family member who could is not well-versed enough to do it. So anyway, so no we have not had that conversation. (1011)

Others approached the discomfort and considered the possibility of their own death prior to the death of the PWD. However, even they had not made specific financial plans related to end of life. For example:

And that's um, that's more like when I retire from the VA and a big chunk of my retirement income, um, my retirement uh, pension, a big chunk of it is health insurance and also I took out for him having annuity. So, if I pass away, he would get like 50 percent of that. And so, uh, you know. That, that's one thing that I prepared for. I wanted him to be taken care just in case, if I uh, pass away before him. You know, so um, and I think it would be well enough income for them to really take care of, you know, take care of him and be put in an institution or something like that.

One individual shared she had never thought about it and highlighted a commonality—that no one thought they needed to plan for such decisions at their age. This held true across Caregiver age:

Interviewer: Have you had discussions about what to do if something like this were to happen, if one of you were diagnosed with any type of cognitive decline or chronic or terminal illness?

Care Partner: Never.

Partner:

Interviewer: Never. Did you have any discussions about end of life care planning?



Care            Um, well, as soon as we found out, we did. (laughs)

Partner:

Interviewer: As soon as you found out-

Care            It was kind of like, "Okay." Yeah. I mean, you know, we were, we figured we  
Partner:        were, you know, you know, younger. He was 59 when he was diagnosed, and  
I'm eight years younger. [inaudible] you know- I was like 50, mid 50, you  
know, mid-50's, so, you don't think about that really. (1012)

For others, the desire to keep their partner at home was so strong that they reported there would be little to no value in planning for future care needs:

Well right now I'm planning on, because before he got sick, we talked about something ever happened. He doesn't want to be put in a home and so I'm going to keep him home even if, as long as possible. Hopefully you know, till the end. And so that's why it's important to me to take care of myself and make sure I'm healthy enough too so I can fulfill that need. And so no, I'm not planning...But I'm planning on him staying here as long as you know, because that was his desire. (1015)

Caregivers highlighted the importance of anticipating costs when preparing for financial uncertainty and acute financial changes. This informs the ability to engage in an array of planning and decision-making tasks. Many caregivers highlighted where they had built in room for adjustments or temporary debt if they needed it. For example, one individual discussed the importance of credit cards, a healthy credit score, and the ability to potentially take out loans:

Oh. We're not really worried about it cause I mean we still got some adjustments that we can make, you know, we're paying off the credit cards, but if something, some emergency came up, we got the credit cards. We can always look for a loan to pick up the slack. (1000)

Others highlighted how unprepared they had been because they had envisioned and planned for a specific lifestyle during retirement:

We never talked about planning for something like this. Not at all. Because- because we were just- you know, we were both gonna retire, and we both would have retirement, and we were gonna travel. So I didn't think much about it- it was just all so very unexpected. (1006)

Some individuals described how the planning never feels like it ends because the PWD's level of

functioning is frequently in fluctuation and you never know what might happen. One specifically described never feeling prepared. She shared that, over time, she stopped engaging in so much planning because there was no certainty and even when she planned, she felt unprepared and like she couldn't anticipate what they would need:

I never know what the next phase is. But you know that's how we handle sort of current expenses- one thing at a time. And again, I'm very grateful we have very open discussion. But we have talked about long-term cost. And of course, you know when you have a diagnosis like his, in some ways, you kind of have a glimpse of the future like, you know, most of us is just roll the dice. You don't know. You just never know. (1007)

Finally, some caregivers (n = 4) had attempted to plan for possible future care needs but could not find consistent or reliable information.

I looked at Dementia units, and, and [redacted] was, was very [inaudible] is the director. Um, but that's \$4,500 a month. That's a lot of money, huh? And so, and they take care of his every need, but I'm watching one of the clients here who's there and um, no. [PWD] would just scream, "I'm being held hostage, call the police." That's what he did at [redacted]. He's only gonna be with me. But yeah, I- the financial reality is stressful because I could just be wiped out completely. That's how I'm trying to avoid that is keeping him home. (1007)

Another caregiver shared the following:

And what they said was, "well, you know our apartments are this and our assisted living is this. But if you need someone to sit with you, that's an additional cost, if you need this that's an additional cost." And then my mom is like 88 and lives in this. She still has her own apartment and all but it's an assisted living and they just opened a memory care wing. And they have a fixed cost. But you have to you know how to qualify and your doctor has to say that you meet certain requirements to go there. Anyway, so and that's a I think a real state-of-the-art place. It's in Texas, but it's you know, a real state of the art in many ways. But one of them is, financially they give you a set rate. Then I have a real good friend who's a lawyer [who's helpful]. (1000)

Another caregiver shared that she was experiencing difficulties at the intersection of financial planning for the end of life and healthcare related to the end of life because no professional she consulted seemed to possess competencies in both, and she was unsure how to find such a service:

For example, my brother-in-law is a lawyer but he doesn't know about this kind of stuff. And actually, our lawyer who does wills and things. You know, nor our accountant. Like I asked both of them, "okay, what are the costs? You know like, what is the cost of all this. And they didn't know. And then called up [redacted] and I said, "you know, we're not anticipating being there soon, but we're doing some Financial Planning and what is the cost of dementia care?" And they wouldn't give me a number. (1000)

In sum, caregivers highlighted the many underpinnings and historical- and systems-level factors that influence their financial decision-making and planning processes as they transition into the caregiver role.

**Financial Management.** This theme refers to the new ways caregivers regularly dealt with their money and assets upon assuming the caregiver role. In addition to shifts in decision-making style and approach over time, caregivers described several changes in financial tools. Two primary subthemes emerged that centered on merging accounts and utilizing technology. Caregivers reported these were both two tools they had not envisioned utilizing but had a significant impact on their overall levels of financial stress.

As previously mentioned, a significant portion of caregivers reported they had maintained separate financial accounts throughout the course of their relationships. Many of these caregivers shared that merging these accounts made a significant difference in ease of financial management. Perhaps more importantly, they also recounted the legal implications of separate versus joint accounts if they needed to make financial or other decisions on behalf of their partner. For example, one Caregiver shared:

And when this whole thing started the financial planner said, "We need to make sure everybody's on everybody else's account." Um, and that was good, because now, you know, if I need to look into, well, w- we basically have joint accounts now... And, we-that's good, because then I can make whatever decision I need to make ... you know, moving money into this or that, or the other thing. (1004)

Another shared:

We had separate accounts then, but we don't have separate accounts anymore. But his name has to be on my account because his retirement's going into it and his Social Security. (1006)

In addition to merging accounts, caregivers highlighted the use of technology to allay financial management stress. This was particularly true among caregivers who were transitioning into a caregiving role for an individual who had many ongoing accounts with which the caregiver was not familiar. A significant portion of individuals shared that transferring bills to autopay was particularly helpful. This was even more so the case among individuals who were sharing decision-making responsibilities with a trusted family member. For example, one individual who was particularly averse to assuming the financial decision-making role shared:

Well I just don't like the responsibility. To tell you the truth, I don't want the responsibility. I never have. [My husband] was always terrible with money but wanted to feel like the boss so I let him, but I had my own separate account to keep us afloat because he was always drinking and gambling it away. Finally, when he was diagnosed, I didn't have to worry about that anymore. Now as I have gotten older, my son thought it was appropriate to step in and help manage the money. I'm not sure it was necessary, but it helps my children feel better. He set us up on one of those apps and he handles our money. I make the big decisions [like downsizing], but he does the nitpicky stuff and man I've never been happier! I'm just not money aware, and I like to give lots of things and money [to my grandchildren]. (1002)

For others, technology was seen as a great gateway to essential information for developing well-informed strategies for financial behavior:

Care Partner: Yeah, I just went online. I'm tech-savvy, you know. I have to be. Everything is electronic now, huh?

Interviewer: Mm-hmm (affirmative). Did you feel prepared for having to do that?

Care Partner: Yes and no. Uh, it was and... I had a sister-in-law, I had his sister who, uh, sent me some podcasts-...of. And I also asked one of my colleagues who is not only a professor but also a lawyer, um, and he helped me with some of the issues that could come up with elder care...and how they could take your money. Uh, and, and I learned very quickly that those nursing homes can... can take everything of mine. Not just his, but everything of mine. (1006)

**Motivation.** This section explores the primary reasons and desires caregivers cited for engaging in financial behavior. Motivation is very similar to values; however, there is a key difference. Motivation stems from values, but encompasses a willingness to engage in action whereas values refer to underlying qualities that render that action valuable. Caregivers cited many motivations primarily concerning emotion regulation and perceived safety and comfort of their loved one. This far outweighed any financial priorities either in terms of tangible resources or planning. Distressing emotions, either experienced by the caregiver or the PWD were cited many times as particularly salient as an underlying mechanism driving caregiver behavior. Caregivers highlighted the need to chronically and “consistently” manage stress levels and negative emotion, but merely to maintain a level perceived as stressful and unpleasant at baseline. At times, this might lead to avoidance behaviors for things such as planning because the need to regulate their own emotional response took priority. Additionally, caregivers cited their partner’s quality-of-life given limited time horizons as their greatest priority. This was even the case when asked about ensuring resources that could sustain through their caregiving role in order to have resources for their own care at end-of-life. For example, one participant shared:

Yeah, it's quite stressful because my day never ends. I'm constantly making sure he has his medications and everything to be safe and comfortable and thinking of what I need to do next. Not only for him, but what I need to do for myself. I've gotten older, so there are doctor appointments that I have. I'm juggling something on a regular basis. It's like, you're constantly rearranging your schedule because, as you understand with this situation and condition, uh, you just take one day at a time. Play it by ear 'cause something is going to jump out at any minute. I gotta be prepared. (1010)

Even within the context of financial strain, some caregivers (n = 3) reported they were willing to spend beyond their means to ensure perceived comfort, quality of life, and safety:

You have to prepare yourself for a different change every day. To find places, long term, that will assist your needs as well as your loved one's needs. Be sure that they are safe environments and, if you can, put away something financially for hard times, definitely

do that. But, be sure, most of all that they are getting the care that they need. At *whatever* cost. (1010)

Another shared:

I mean, you know, we're not gonna put him in a nursing home. So we just gotta take it as it comes. that's where you just got to cope with it and you got to pass it off like, "you know, it's okay and you pamper him." If he gets upset about something, say, "it's going to be okay. Don't worry about it." (1000)

Another shared:

Because he's starting to- he's starting to have, like, very obsessive, and he's gotten way more obsessive, and so there are certain things he obsesses about. Like every three or-three or so months, he'll say, "I don't even know how much money we have." And, I'll go, "Okay. We have five accounts, in there we've da da da, and this is how we." And, I'll go over them, and then he'll say something like, "Well, we need to meet with our, you know, our financial guys." And, I'll go, "They're happy to meet with us anytime." So we'll go there, and they'll explain it all to him. And he'll go, "Oh, well I didn't know that." And then we'll come home, and he'll go, "I feel so much better." (laughing) And then three months later, he'll be stressed about it again. And, yeah, it takes a little extra for me to do that, but I feel like I need to do it that way, want to do it that way. (1004)

Overall, caregivers seemed most motivated to engage in particular decision-making patterns driven by emotionally salient content and intrinsic values. This was further complicated by discussions, attitudes, and values about death and quality-of-death and control over death.

**Capacity.** Caregivers described their ability to use their available skills and resources to manage adverse, risky, or problematic financial conditions or situations. They indicated that their ability to engage in this behavior was also contingent on awareness and management. As caregivers' reported capacity to respond to stressful experiences increased, the likelihood of engaging in financial decision-making or planning about future care decreased. Many caregivers (n = 11) highlighted low perceived control as a contributor. They reported the prognosis for their partner's disease progression and functional ability as so variable and unclear that planning seemed pointless. For example, one caregiver shared:

And, it's happened twice now, and so our financial planner said, "Yeah. We can [budget for x number of years], and you'll be okay. But I don't know if I can trust that. He might live another month, he might live for ten years. So what do I do? (1001)

Caregivers who also described high levels of confidence or self-efficacy in their abilities to make effective financial decisions given past experiences were even more likely to engage in reactive decision-making and "crossing that bridge" if or when they must. Greater perceived income adequacy further decreased the likelihood caregivers would engage in financial decision making about future care. Individuals who identified as being more support seeking reported this greatly impacted their ability to engage in financial decision-making and reduced their financial stress:

So I guess those those would be my tips. Oh, oh and one more. Friends who are going through this. And I wrote it off real quick, but like there's a support group that that we both went to and it was really awful. It was really, you know dominated by some weird personalities and very negative and very rigid. But I think that's really the only Dementia care group for caregivers in town. So I don't go there anymore, neither does my best friend. But she and I can talk all the time. And then a person we don't know very well, but a good friend of mine from out of town connected me to a friend. I mean a woman that we barely know but [redacted] and I are going to meet with her tomorrow for lunch and I've met with her once and I think the three of us will kind of have our own little group. So really, to get friends who are going through this, but to to choose wisely your friends that you're going to talk with about it. (1011)

Unexpectedly, this also appeared to be a barrier for making financial decisions about end-of-life. For example, one caregiver shared:

Well, my three children came down and had lunch with us one day. And they said... They were just saying we were getting so old and they didn't realize we were that old, you know. And we're so isolated. And with Mercedes having opened up the traffic had increased. So they were concerned for our safety, and they could tell that [inaudible] the house, you know... So when my son, you can't do such and such, we only have so much money. And such and such is doing that, I say, thank you mother [Laughing]. And yeah, we laugh. It's an interesting reversal of roles, and I think that happens as you age. You know but he's very um, systematic and organized and he doesn't make decisions without consulting especially the daughter... So you know, he's closest to a computer. And when a decision that needs to be made that is really serious, [everyone] consults him. Send him a notification, computer-wise. It's wonderful being able to have children that can do that kind of stuff. And well I don't want that responsibility. (1002)

**Resources.** Caregivers described their lived experience of resources in terms of objective resources (e.g., income) and financial literacy. Caregivers noted an increased ability to engage in reactive decision-making if a crisis were to emerge. Therefore, caregivers did not believe financial decision-making about the future was “worth it” (n = 11). This held true even in cases in which caregivers reported feeling financially stressed. For example, one caregiver who reported moderate levels of financial stress shared:

Well, the fact that I haven't really made any plans is probably a product of some avoidance. Now, I would say, yeah, that is an element in it. I probably should have more plans in place, more contacts established, but things are going all right, right now, but I think I have to... I do see some deterioration in language ability, but nothing that I have to act on right now. I'll do it when I absolutely have to. I'm not really worried about it, we have enough money and assets for when we need it. (1018)

Another who reported feeling financially stressed, but who also had made extensive medical-legal decisions regarding end-of-life reported:

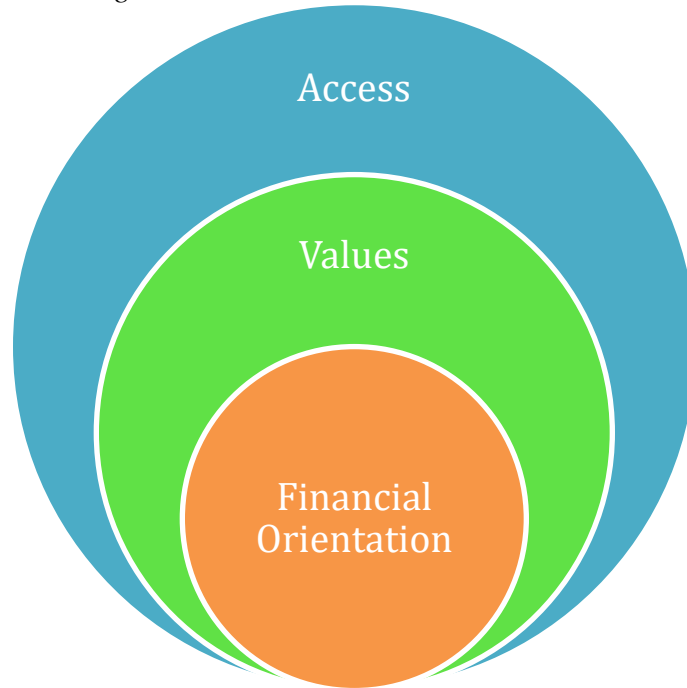
And financially, we are set. “I hate to sound this way, but we have always been so well off that I wasn't paying attention to where the money was going or where it needed to go. (1004)

Even after attempting to discuss financial decisions with her long-time and “trusted” financial planner, the caregiver reported being told the following:

And- And they said, "You're right. You're right. And, you got plenty of money, so don't worry about it." "Okay." (1004)



**Figure 4.**  
*Theoretical Categories*



**Values.** As Caregivers shared their experiences of financial stress, strain, and decision-making, they frequently referred to their values. Values refer to the degree of importance of caregiver beliefs about behaviors and ways of living, and frequently guide the setting of behavioral goals. Primary themes within this category included effective caregiving (versus exemplary caregiving) and end-of-life planning. This is discussed regarding current and future care, quality-of-life, and quality-of-death for both the PWD and caregiver. Values were described as determinants of patterns of thinking about caregiving, what made a “good” caregiver, and strategies that were most effective in terms of meeting a specific goal (e.g., decrease PWD distress). At times, caregivers noted struggling when they were unsure what their partner’s values were related to financial decisions which increased financial stress. Caregivers discussed having their own values, knowing what some of their partner’s values were, and having some shared values. However, particularly when discussing end-of-life, caregivers

insightfully highlighted they were experiencing this uncertainty because they avoided these end-of-life-related discussions with their partner. In some cases, this uncertainty stemmed from including other family members in end-of-life discussions. For example, some caregivers (n = 2) noted children were uncomfortable when discussing withholding food and water. Moreover, caregivers reported greater financial stress if what was best financially violated their values or their partner's values. Some reported feeling there was no solution that was fiscally responsible and in line with both their values and their partners values.

One caregiver reported she had attempted to have a conversation with her partner about her values concerning end-of-life, and she refused to engage in the conversation:

I talked about that. I uh, talked to her about, she doesn't like to talk it about though, but I talked about, you know, about final arrangements and uh, you know, that kind of thing. (1009)

Another shared about her experience attempting to have a conversation about what she and her partner valued regarding end-of-life. Her family did not agree with their values, which was distressing and made it difficult to move forward with formally arranging for the decisions they had decided on together:

And then too, it's really important to have conversations about it and your family. I think probably the hardest conversation that we had in all of this, was about our advance directive. Our kids were not on board with that at all. It was like, my son said "what are you talking about?" And we really have talked with them a lot and they understand and they're supportive. And I have not yet been in to see my you know internist yet to have the conversation with her. And she's very conservative and religiously conservative so she may not be on board. I don't know. But our neurologist at [redacted] and the internist were completely on board and very supportive. But I mean you probably know like the way that would precede. You stop eating and drinking at home, then you need a physician to you know to make it go smoothly too. Essentially, you know transition you to hospice and so both of [PWD's] doctors that we've talked to have said they will do that... We need to redo our wills and our Advanced directives. Oh so he brought it up. But I do remember, we were in a book club, which we've dropped out because he really [PWD] can't follow it and he was uncomfortable. But one of the books we read was Being Mortal by Atul Gawande. And you know, we read it before [he was diagnosed] but

the power of that and just the power of what he said of watching people go out on their own terms and figure out what's going on. (1011)

Many individuals (n =7) reported although they had discussed some end-of-life issues such as life sustaining treatment, they had not discussed the associated financial decisions they may need to make or for which they may need to prepare:

Interviewer: Did you and your husband have any discussions about how to handle things financially should one of you get sick?

Participant: Not really financially. We discussed over, when we got real sick, we would not um, be kept alive you know, like not any type of life support or anything like that. We talked over that...we probably should have had those discussions.... And now before he got sick, well he just couldn't work, the mental problems weren't there. He's the one that insisted on this, doing, going with this type of loan on the house and stuff. I guess it was that he was probably looking out for me, you know later. (1000)

When caregivers were feeling conflicted about how to make end-of-life decisions that would influence financial decisions, they reported feeling much less stressed if they had support from family members. For example, one caregiver shared her children had initiated this conversation, and she realized they were feeling stressed about it as well. She shared they all felt much less stressed after having this otherwise challenging conversation:

You know, so he got to where he couldn't [inaudible]. But anyway, I have three children, I'm grateful for that. And um, we sat there and talked and you know... [redacted] says, what do you think your future looks like and what are your wishes? Kind of thing. And he's taken notes, he's very forward. And my daughter... The main thing is just saying that[inaudible]. And have been very cooperative, and he understand, and their solution was to put dad somewhere. And I said, well that's all right when he's ready. (1002)

Another shared a similar experience:

Interviewer: Is that something that you guys ever talked about? Is it something you're thinking about?

Care Partner: Um, you know, we, we talked about it a tiny bit before. You know, like, um, like even with myself um, assisted, assisted living, something like that. But my daughter actually, uh, brought that question up a few weeks ago. She said, "Mom, would you ever consider [inaudible] dad away

[inaudible]?", and I said, "Well as long as I'm able to physically, mentally, able to care for him, uh, I'm gonna do it."

Interviewer: Have you met with anybody about financially how to plan for that, if it were something that needed to be considered?

Care Partner: Um... no I haven't. But since you mention it, you know, I would probably mention that to my uh, financial advisor. (1009)

Another shared that she had a desire to initiate these discussions with family members, but they were unwilling or unable to do so:

I would very much like to [have those financial planning and end-of-life discussions] but his kids went through a lot. Their mom was sick for a long long time and for better or for worse the coping skills that they developed are denial denial denial. And do not feel comfortable at all talking about scary stuff or reality or...And he's not really able to. (1011)

Another discussed the importance of sharing what your values are in terms of finances and end-of-life with someone you trust other than your partner. They highlighted this is important to do very early on in case anything were to happen to them:

So that uh, and I say all, you know, I... Really, just because you discuss it, doesn't mean you're going to die. It just means that you, you're gonna be prepared for whatever it is to come. And you know, you could live for years and years- I talked about that. I uh, talked to her about, she doesn't like to talk it about though, but I talked about, you know, about final arrangements and uh, you know, that kind of thing- So I had... What I did is I started writing things down about uh, you know, what's to be done, what's um, what monies is at the bank, the account numbers, and all of that. (1008)

Other caregivers were forthcoming about reasons they might be actively avoiding having these conversations, reflecting on values, or engaging in planning. Many caregivers (n = 9) reflected on distressing emotions and fear of the coming reality (i.e., death of their partner or themselves). For example, one caregiver noted the need to plan and speak with a financial advisor, but had continued avoiding doing so:

Care Partner: And then they have a homemaker that comes in and cleans my house so I'm fortunate there so far, but hospice is not gonna come in 24 hours a day. I'm worried about having to make that decision. And it's coming quicker than I anticipated it would, huh?

Interviewer: Where are you at in preparing yourself to make that decision?

Care Partner: Yeah, I'm avoiding it right now because you know, it's just the reality of it is very scary.

Interviewer: What supports do you feel like you need to prepare yourself for that?

Care Partner: I guess I need to talk to a financial advisor and find out what to do with the money that I have in savings.

Interviewer: Have you talked to a financial advisor before?

Care Partner: I- I talked to one at Regions, uh. And so- so I'm about ready to put the money I have in savings in something else, huh? So- so it can't be touched. But there's- there's not- there's not much you can do. Once they go into a nursing home, they can take anything you've got anywhere. (1006)

Like the caregiver quoted above, many cited not knowing when the “right time” is to do these things:

Interviewer: Right. And so since- since his, um, since his diagnosis, how have you guys been planning financially in terms of health care and end of life?

Care Partner: Um, there's been not too much of that. Healthcare, we're, you know, he's pretty much taken care of with what he's got, 'cause he's on social security plus a supplement. Um, you know, we haven't thought about anything farther than that, (laughs) to be honest, you know. Yeah. I mean, like- like, if you're talking like, um, having extended care or something like that, kind of, a policy, we- we haven't even thought about that kind of thing yet.

Interviewer: Right. Do you feel prepared to- to start planning for things like that? Or are you kind of at the point right now where you're like, "That's too much, and- and I need to not do that right now."

Care Partner: Yeah. I need to not do that right now. Actually, he is functioning well enough, I don't have to worry about something like that. At this point, I don't see any problem that it would be a- a- in the- in the immediate- in the immediate future, for sure (laughs)... You know, I mean, it- it could be a lot worse. I mean, you don't know what tomorrow's gonna bring. I mean, if I get sick or something

happens to me, there's a whole nother, you know, story to that. But, um, right now- right now, this is okay.

Interviewer: Is that something that you all are prepared for?

Care Partner: No. (laughs) I finally got health insurance, (laughs) which was good. (1012)

**Access.** The third category identified as inextricably linked with caregivers financial stress and financial decision-making was social access, the ability to obtain, examine, or retrieve power, resources, or information. caregivers discussed access within the context of 1) navigating healthcare, social, and legal policies and procedures, and 2) obtaining specific tangible social and healthcare benefits. For example, one caregiver shared:

Well we just started out on social security from him and I had to wait until I turned 62 before I could draw my Social Security, which I went ahead and started drawing at 62. Because financially I had to, because I was here with him. So now I've turned 65 so that's helped a little bit but there was like three years there that I didn't have any health insurance because the Obama deal was, it was high and your deductibles was high, so I figured well you were going to lose what we got, might as well just to lose it, but we can take a chance on it. But Lord. I didn't have any kind of medical problems other than just taking blood pressure pills and just like that cholesterol. That's all the things I ever took so we made it through that. So now I've turned 65 in December and so I'm on Medicare coverage now... And probably the most that we spend now would be on life insurance because I know we won't have the funds... I won't. If something happened to him I wouldn't have the funds coming in because I could only, I can draw his up to what his Social Security is. So you're looking like thirteen, fourteen hundred dollars. And I don't know if the VA, if they pay the spouse anything. I don't know. (1000)

Another shared:

I had to take care of all the hospital bills. I had to take care of all the financial needs. I had been taking care of some of them, but then I had to find out about Medicare and, and how much Medicare was gonna cover of all the services that he needed at the time. Fortunately, they did. Medicare and Blue Cross Blue Shield C-Plus took care of most of it...also, he has Social Security, and I have Social Security so that's how we stay so financially secure...I even thought about moving back to Maine because they have MaineCare. It's socialized medicine. Massachusetts and Maine have socialized medicine. (1006)

One caregiver thought she had planned, but soon realized after assuming the caregiver role that she had underestimated how quickly she would deplete her accrued savings and benefits:

Uh, with the financial decisions, I... I've... I had retired and you think, well you know, your retirement is gonna last forever. Not true. You know, because it... Soon, it's depleted... Because you have uh, so much other stuff that you're doing uh, with regards to uh, doctor's visits. Buying different things to make them comfortable. Depends. Being in the hospital. (1010)

Another caregiver shared how challenging it was to navigate the guidelines of accessing and securing various social benefits:

That the person can do that have very little means. Unless our government is gonna kick in and take care of the elderly people that have told for years and when they reach their golden years, then they are just kinda pushed aside.. With very little assistance. If you're two dollars over a guideline, then you're- you're- you're doomed. You- you can't get assistance to pay your power bill or to keep your li... Uh, gas or water, you know, those kinds of things. That's where I believe our system has failed us or the failed the elderly. I don't even know um... Uh, I don't know. I- I guess I just think a little bit too deep about all of that stuff. With the aging of people. You- you really worked hard and if you need food, you can't get food stamps because you're over the guideline and you've got to exhaust all of your means and become really poor than you are to get assistance with food stamps (1010)

One caregiver highlighted the importance of accurately navigating legal aspects of caregiving, particularly in terms of exerting control over quality-of-death:

And we have very strict living wills, and it actually says, "When either one of us are in stage 6 [inaudible], of dementia, if we lose interest or fight against eating and drinking, we stop offering it," which our law- lawyer said that, that's legal, as long as you've done it before, you know, you- you put all of that in place beforehand, in which we have. (1004)

Um, with that. And one other thing which I have to do because years ago, probably like, 2008, 2009, uh, he and I we went and we did our will and we did do a power of attorney. And what helped me with that is, that was the time when I got transferred to work in the home-care program at the VA and dealing with the elderly I had to do a lot of uh, help... assisting them with advanced care plans. So that opened up my knowledge. (1009)

An important component of access was highlighted within caregivers' social networks.

Individuals of higher class appeared to have access to social networks that were more highly

educated with access to valuable personal and professional information. One caregiver pointed out:

Well, both of my kids and then [redacted] and I are very close and obviously traveling, somewhat, this same journey [caring for our partners who have dementia]. And my accountant, who I trust a whole lot. And our lawyer who drew up, you know, we now have new wills, you know with the financial power of attorney and advance directives and she's a good friend. I've talked with her about it. And then I am so fortunate you may know, it's [redacted]. Anyway, she developed a whole series of courses on personal financial planning and taught for 30 years and she's a good friend. She's wonderful. So I called her up and I said, Okay, [redacted], Can you consult with me on this or if not, can you recommend somebody else. And she said well of course, I'm happy to. And I went through everything with her and and you know, she's given the same advice as again... My kids are very financially savvy. Exactly, what I thought it was, exactly what our lawyer, exactly what our account, I mean it's so, you know, I feel confident that you know... I mean you never know what's going to happen. But you know, I have a pretty accurate sense and it's just I would rather not be the one to have that conversation with the kids. So but you know, there are other people that could. Like they both know and really really like our lawyer. You know, so she could be the one that would say you know, we need to just make sure everybody's on the same page. So when we get... When it's appropriate, I don't know when it is appropriate, but that's probably how I would do it. Is let her handle it. (1011)

Stigma (maybe include when discussing recruitment)

But he said you know Alzheimer's has a stigma like AIDS was and being gay is and it ought not be. And I'm the face of Alzheimer's and I want people to know that. Because that needs to be said. And we went to dinner and he told some friends and he said I want you to tell other friends of ours because I don't want people to think that if I'm relating to them differently it's because of him. And so I can't imagine anybody being braver. You know. (1011)

To summarize, caregiver described their lived experience of financial stress as complex and nuanced. They described many domains within the category financial orientation that influenced their level of stress beyond objective income or perceived income adequacy. Underpinnings of financial stress included their perceived role in financial decisions-making, their self-perceptions of their decision-making style and approach, their financial management and planning strategies, and their perceived confidence, self-efficacy and skills.



Furthermore, caregivers shared a multitude of ways financial stress manifested during their decision-making process. It manifested in terms of detecting, perceiving, and responding to threats. It also emerged as influential on perceived abilities to respond to threats. Overall, it appears financial stress is much more complex than extant literature has observed or reported or that extant assessment methods have measured. One reason for this gap may be avoidance on the part of caregivers and a lack of existing research and clinical infrastructure in integrated care systems to raise the issue for consideration and future planning. This offers valuable information about caregiving processes and yields rich insights for intervention development.

## DISCUSSION

This study was an in-depth exploration of caregivers' lived experience of financial stress and how it manifests during and impacts dyadic decision-making. It further explored potential convergences and divergences in study phenomena across income level. Previous quantitative and qualitative research has highlighted a shortcoming in how financial and class-related aspects of one's experience influence psychological processes (e.g., stress & coping, Sun et al., 2009). While research has suggested income and appraisals of income adequacy are important facets of the caregiving experience, little is known about its function or how it impacts caregiver wellbeing, quality of care, or decision-making. This study expounds on the extant literature and makes specific key contributions in several domains. Specifically, it contributes greatly to our understanding of caregiver-specific financial stress and yields insights for scientific, clinical, and policy domains. This study revealed financial stress is a complex and nuanced construct with perceived importance to dementia caregivers that is experienced differentially and independent of income or perceived income inadequacy.

Additionally, it revealed novel phenomena concerning an oft used avoidant and disengaging coping style at the intersection of financial stress and end-of-life. These phenomena manifested differentially across income levels (low, medium, high), but the outcome was consistent for all groups—avoidance of planning financially for end-of-life (e.g., long term care, future financial needs of the caregiver). Surprisingly, even though caregivers had discussed medical decision-making for the end of life or endorsed high levels of financial literacy and

financial planning (e.g., retirement, savings), not one caregiver reported having planned financially for end-of-life specifically. These findings have uncovered a significant gap in research and structural clinical and policy arenas (e.g., integrated models of care). It also adds clarity to our current understanding of Advance Care Planning needs and an opportunity to improve dissemination of information and resources within our healthcare systems and communities.

### **Income and Perceived Income Adequacy**

This study uncovered eight primary components of caregiver financial stress orientation that significantly impact financial stress and shape both how they caregivers cope and make decisions. This is a construct that has been poorly operationalized to date, and often income and perceived income inadequacy are used to denote financial stress in stress and coping models. Consistent with previous findings, income adequacy and income were not significantly related. However, as perceived income adequacy increased, reported financial stress decreased. This is important given how frequently income is used as a proxy for financial stress. This inaccurately assumes those with lower income are more financially stressed. These findings robustly suggest this is not the case, and the operationalization of the financial orientation construct revealed in this grounded theory provides new areas for assessment of need.

### **Financial Stress, Coping, and Decision-Making**

When asked about financial stress, caregivers consistently identified financial decisions about end-of life for their partner, and occasionally for themselves, as the greatest threat to homeostasis. Our hypothesis was caregiver's would appraise financial stressors as a threat when they did not believe they had the resources to meet the demands. Unexpectedly, although *all* caregivers reported it was a threat, they also believed they had the resources to make those

decisions when needed. However, upon follow up, qualitative findings suggest this is not the case, and there is great uncertainty concerning what resources they would need. Therefore, although caregivers reported great self-efficacy and were even able to identify resources they would potentially access (e.g., social network, social benefits), they are not engaging behaviorally in adaptive coping, planning, or making financial decisions regarding end-of-life. In fact, they are disengaging and employing avoidant coping (e.g., minimization). Given caregivers consistently reported this was their greatest source of strain yet proclaimed they had the resources to address it, this suggests their avoidant coping functions to decrease distress in the short-term, but serves as a feedback loop for negative affect, and increased stress over time.

In combination, several theories offer a possible explanation for this unexpected finding. Per Motivational Theory of Lifespan Development (Heckhausen, Wrosch, & Schulz, 2010) and Selective Optimization with Compensation (Baltes & Baltes, 1990), individuals focus more frequently on emotional content and compensation strategies to cope with loss. These theories suggest older adults rely more frequently on secondary control strategies such as avoidant coping and disengagement. This is consistent with our finding that caregivers reported they were more frequently engaging in a reactive decision making style.

Additionally, Socioemotional Selectivity Theory (SST) suggests that as time-horizons shrink, there is a motivational shift towards selectively attending to present-oriented goals that prioritize meaning and emotional satisfaction over long-term goals (Carstensen, 1993, 2006; Carstensen, Isaacowitz, & Charles, 1999). The present findings suggest financial end-of-life planning is not congruent with the context of these similar but nuanced motivational frameworks. Therefore, perhaps unsurprisingly, caregivers engaged in avoidant coping and/or disengagement as a means to employ secondary control and mitigate negative emotion.

Upon closer investigation, it appeared this avoidance and disengagement phenomenon manifested differentially by income level. All participants reported high self-efficacy stemming, in part, from having been involved in financial decision-making historically. However, reported secondary appraisals of resources varied by income level. Specifically, individuals of lower income more frequently referenced they would rely on their support system and family members for end-of-life care support if they felt financially strained. Individuals with higher income and perceived income adequacy reported they had enough money to deal with end-of-life financial strain if needed. Despite this difference, frequent acknowledgement of its importance, and a desire to engage in such planning, **all caregivers reported they had not engaged in end-of-life financial decision-making.** They also verbalized a more reactive decision-making approach in which they would “cross that bridge when they got there.”

In addition to motivational shifts consistent with SST, it is possible there is also uncertainty about regulatory orientation and regulatory fit (Higgins, 1997) when confronted with an end-of-life financial decision. Regulatory Fit Theory (RFT) suggests motivational strength increases when there is congruence between regulatory orientation (promotion or prevention) and the behaviors individuals engage in to achieve a goal.. The fundamental assumption is this is derived by choices individuals make to “avoid pain and pursue pleasure.” However, death is more complicated and all decisional paths, promotion or prevention oriented, lead to death, igniting both painful *and* pleasurable emotions. This would explain why no one combination of decision-making approach or style facilitated engagement in financial end-of-life decision-making.

More interestingly, despite caregivers’ avoidance of making financial end-of-life decisions, many discussed their values about death and where they and their loved one would

prefer to die. Surprisingly, many had engaged in advance care planning and had documented end-of-life medical decisions (e.g., life sustaining treatment, withdrawal of food and drink with the support of a medical provider and legal documentation). Therefore, it is clear that even in the context of death, there is something fundamentally different about making an end-of-life medical decision and end-of-life financial decisions.

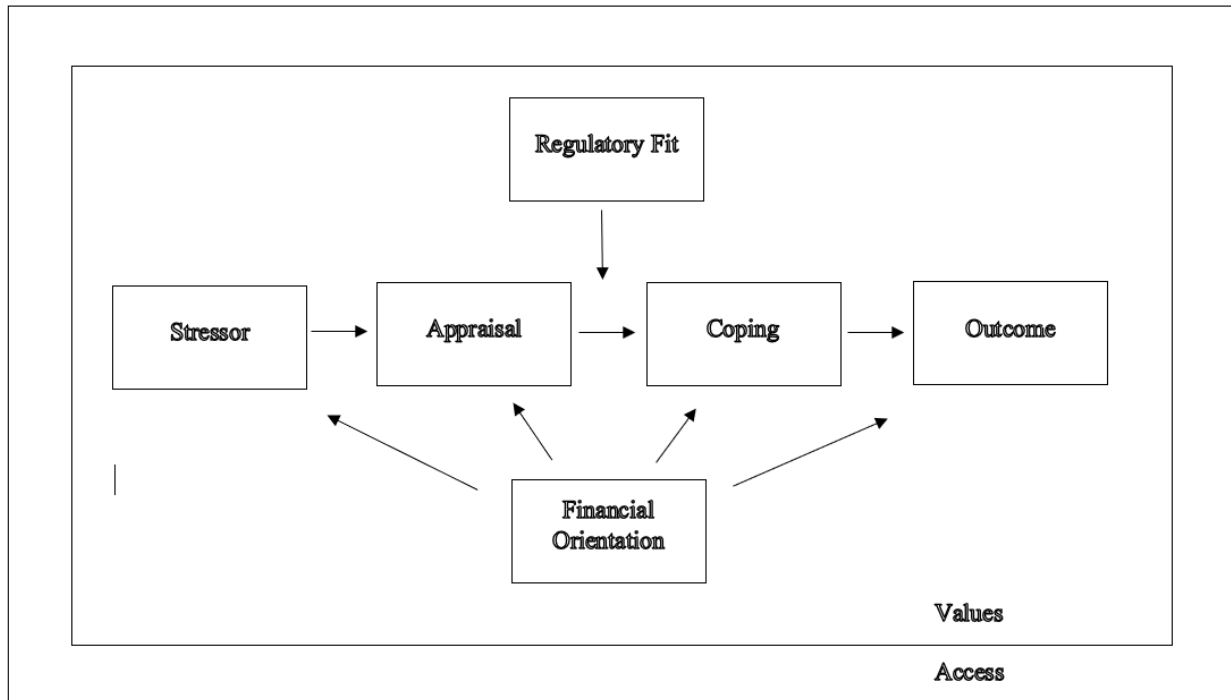
Park and Sela (2018) recently tested an adapted regulatory fit theory that may offer enlightenment. They posit that individuals often lean towards a decision style more nuanced than promotion-oriented (i.e., making decisions to promote pleasure) or prevention-oriented (i.e., making decisions to prevent pain) to include an affective or analytical decision-making style (i.e., approach theme). They suggest that anticipating or experiencing fit between perceived decision-style (continuum of affective to analytical) and decision type increases task engagement. Otherwise stated, when considering underpinnings of our defined financial orientation category and themes, motivation strength would increase as congruence between type of decision and decision-making approach increased. They also suggest financial decisions are often considered more analytical in nature. If this is the case, and caregivers have shifted their motivations and more frequently selectively attend to affective content, it explains why our sample, despite varying underlying mechanisms, disengaged from making *financial* end-of-life decisions. Perhaps financial end-of-life decisions are perceived as more analytical than affective compared to medical end-of-life decisions. Additionally, there is more cultural discussion and encouragement of medical and legal advanced care planning (ACP).

The degree to which one more selectively attends to affective content is likely highly individualized. For example, an individual who is highly analytical in their approach to decision-making may shift somewhat as they age, but this does not necessarily indicate a significant shift.

In our sample, there were individuals who attempted to make end-of-life financial plans but were consistently confronted with lack of useful information as well as competing information. This resulted in uncertainty and feelings of incompetence or powerlessness. Therefore, individuals utilized secondary control processes by disengaging and reverting to appraising their resources and embracing a more reactive approach.

In sum, these theories in combination with the qualitative data in this study offer rich insights into new elements of a financial stress and coping framework present in this population. In addition to appraisals of threats and resources and abilities to cope, there is also an appraisal of regulatory fit and self-perceptions of decisional approach (see **Figure 5**). This offers a novel dimension of caregiver stress, coping, and decision-making that has yet to be explored, revealed in the financial orientation category.

**Figure 5.**  
*Theoretical Model*



This study further elucidated, for the first time to this author's knowledge, the fundamental features of financial stress and its impact at all stages of the transactional stress and coping process (Lazarus & Folkman, 1984). Findings suggest an individual's financial orientation serves as a lens through which threat detection, appraisal, regulatory fit appraisal, resource evaluation, and coping occur (**see Figure 5**). This highlights the need for a more nuanced operationalization of financial stress that considers the eight domains identified in the present study, which included financial decision-making role, style, approach, motivation, management, capacity, and ability. Often in literature, income or income adequacy is used as a proxy for financial stress. This study highlights why this is problematic. Financial stress is highly individualized and influenced by both personal and contextual factors. It further manifests throughout the stress process and influences stressor detection, primary and secondary appraisals, and coping.

### **Gender and Power**

Notably, some of these findings further clarify our understanding of the role of gender and class in terms of access and power. Unexpectedly, female-identified caregivers reported having always been involved in financial decision-making, at least to some degree. Research has suggested that men most frequently made decisions in relationships; however, these findings suggest shared financial decision-making is more complex. The present findings suggest that women are frequently involved in financial decision-making over the course of their relationships. This appears to increase self-efficacy and confidence in financial management upon assuming the caregiver role. In fact, these findings suggest care partners historically maintain separate accounts and split financial tasks. Women frequently reported managing most daily expenses (e.g., groceries, utilities), while men managed retirement policies, pensions, assets



(e.g., estates, stocks). This was also somewhat true in same-sex relationships wherein other male identified family members or fictive kin were selected to aid in those decisions.

Although historical involvement in decision-making appeared to increase self-efficacy and confidence, it is plausible it also places these women at risk for financial mismanagement or exploitation given their lack of experience and knowledge about how to manage these higher order decisions. Their high levels of self-efficacy and confidence in their abilities to manage the finances decreased the likelihood they would detect financial stressors or threats, seek necessary financial guidance or information, or engage in necessary decision-making.

Additionally, class issues emerged. Individuals of lower class reported they did not think they needed to seek financial guidance or information about financial planning because they believed their income was not sufficient to warrant seeking professional services. Women who did seek financial services reported they were not able to acquire the information they needed. They reported institutions and financial planners alike were not able to provide specific prices or guidelines for how to make financial plans or decisions for placement or in-home aid. Taken together, these findings highlight a significant issue regarding access to information and power over financial health that disproportionately impacts women. It furthermore highlights a call to action in which public health officials, policymakers, and healthcare providers have the opportunity to better identify individuals in need and improve provision of information and services.

Upper class caregivers reported they had a financial advisor or planner who they would rely on to manage decisions for them if needed. These individuals did not seem to have considered the necessity to “spend down” or liquidate assets to meet some of their goals. Therefore, despite having higher income and access to resources, they too were engaging in

behaviors that were avoidant and increased later financial risk. This sheds light on several class-related issues in healthcare. First, this introduces the opportunity to improve integrated healthcare systems by either providing training about identifying these individuals and connecting them with appropriate services or expanding healthcare teams to include individuals competent in financial-legal arenas related to end of life (e.g., psycho-medico-legal-fiscal partnerships).

Additionally these findings highlight the need for varying degrees of intervention type based on the needs of the caregiver. It is possible some caregivers require more psychoeducation-based interventions, some would benefit from more emotion-regulation and distress tolerance skills, and some would benefit from an integration of the two. To date, caregiver interventions have frequently been primarily psychoeducational in nature and “one size fits all.” These data underscore the importance of more complex and flexible multicomponent interprofessional interventions (see Zarit, 2018 for a similar call to action) in order to enhance access, equality, and equity.

### **Limitations**

As in any research, this grounded theory has its limitations. The intention of this study was to maintain a relatively broad context of exploration given the novelty of the of the target phenomena. It is possible there was selection bias within our sample; given how frequently avoidance was described, it is possible the caregivers here may be unique in their willingness to discuss their experiences of financial stress and decision-making in the context of caregiving. Moreover, recruitment of individuals with dementia was not feasible, as our sample included eight individuals with mild or moderate dementia who were unable to discuss financial issues and stressors. Therefore, this study only includes exploration of facets of financial decision-

making from the perspective of dementia caregivers and thus data are not representative of the dyadic approach, but merely of the perspective of the caregiver. It is noteworthy that this study sample is heterogeneous regarding socioeconomic status and level of PWD impairment.

Although our sample included caregiver reported QDRS and CDR scores that were wide ranging (3.5-20 and 0.5-2, respectively), it did seem that even individuals who were experiencing mild impairment had difficulty responding to interview questions. While it remains important for individuals with dementia to be included in research, these data provide valuable information about how to adapt research protocol and procedures to enhance the quality of information gathered. For example, future research might prioritize recruitment of individuals in early stages, perhaps by using language such as “memory or cognitive complaints” in recruitment materials. It may also be useful for future research to utilize methods such as observing dyads have a discussion about financial decisions. This might address limitations experienced in the present study.

Finally, for feasibility purposes regarding recruitment, this study solely focused on female-identifying spousal caregivers. Therefore, these findings are not necessarily generalizable to other caregiver populations (e.g., men, adult children). They are also not representative of caregiver networks wherein there is not merely one solely identified primary caregiver.

### **Implications and Future Directions**

This study yielded significant implications for scientific, clinical, and policy domains of psychology.

#### ***Scientific***

This study provided an exhaustive and contextualized understanding of dementia caregivers’ experience of financial stress, strain, coping, and decision-making regarding current

and future financial management and planning, resulting in the definition of the new construct financial orientation. The exposition of the underlying categories, themes, and processes in this grounded theory allow for a greater and more nuanced understanding of how dementia caregivers' financial stress and decision-making can be described and considered at the intersection of several extant psychological theories.

Especially salient were the multitude of ways in which psychological phenomena were described by participants when they were asked to discuss the role of financial stress in their lives. Notable clarity was gained regarding facets of financial stress and its impact on the stress and coping process. Future research should focus on these facets of financial orientation as related to stress and coping to further contextualize and operationalize financial stress and understand its function in the stress and coping framework. Moreover, given this study's findings concerning power and access, it is essential this be considered among minority populations for purposes of equity. This would yield valuable information about the caregiver experience as well as how best to design and implement multicomponent interventions.

These lived experiences further uncovered contextual aspects (i.e., values, access) that will be important in the future exploration, replication, and confirmation of extant theoretical processes and models to explain and predict financial decision-making in end of life. The importance of access and values shaped stress processes for individuals. Given this finding and its complex relation to income, it is essential future research also explore these phenomena within diverse racial/ethnic groups, male-identified and gender non-conforming caregivers, and caregivers or other relationship status (e.g., adult children). Research should focus on this differential influence and explore how it manifests among dyads earlier in their disease process (e.g., memory complaints, still making decisions). It is also worth exploring among dyads coping

with younger onset dementia given they are frequently not of age to capitalize on social benefits such as Medicare and may still be caring for children.

### *Clinical*

Particularly salient throughout caregivers' descriptions of financial stress and decision-making was the level of avoidance they engaged in when discussion focused on elements of end-of-life planning. Scientific communities would benefit from further exploring the role and manifestation of avoidance, particularly of financial planning, among caregivers. It is clear avoidance functions to protect and preserve positive emotional states, and it seems a necessary intervention target. However, it is also unclear how and if caregivers understand the function of avoidance as it relates to their values in the realm of financial decision making. It is entirely plausible that such planning is not within caregivers' values systems in which case, intervention design would need to be adapted.

Similarly, given high level of emotion-focused decision-making and resultant avoidance of end-of-life financial planning and decision-making, interventions should emphasize distress tolerance and emotion regulation skills. Similarly, given avoidance of death-related discussions, interventions should incorporate discussing death, identifying death-related values, and working towards acceptance and approach strategies to enhance quality-of-death. The results of this dissertation reveal advance financial planning demands focus, attention, and intervention alongside advance care planning.

Finally, interventions should also integrate psychoeducation concerning budgeting and managing finances. This study seems to highlight a gap in services. Many shared their financial planners and accountants were well versed in many domains of finances, however, they did not seem to know as much about how to manage money to qualify for or ensure funds for placement

or in-home aid if needed. This has highlighted a great need for partnerships and integrated healthcare systems that include individuals competent in behavioral change as well as legal and financial realms related to end of life. Future clinical directions should include exploring strategies to incorporate professionals with expertise in finances on integrated models of care and making information accessible. Possible future directions include development of ACP tools that include a financial component and training current healthcare professionals to identify and engage at-risk individuals in order to education them and connect them with services.

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## APPENDIX A

### Semi structured Interview Guide

1. Historical Context:
  - a. Tell me about how things have changed financially since you have become a caregiver?
  - b. What were things like before?
2. Current decision-making context: What financial decisions arise on a daily basis?
  - a. Tell me about the kind of decisions arise regularly
  - b. Tell me about the kind of financial decisions that arise
    - i. Different types.
    - ii. What has that been like
    - iii. Has that changed over time? How so? What was it like in the beginning when you first began caring for CR?
    - iv. How did the two of you negotiate who makes what decisions
3. Decision-making autonomy: Is CR currently involved in making their own financial decisions and the caregiver's view of this ability.
  - a. Are there any decisions CR makes on their own?
  - b. What is your view of their ability to do so?
    - i. How well do they make these decisions
    - ii. Are there financial decisions you make together? How do you do this?
4. How proxy decisions are made: What information caregivers rely on.
  - a. How do you go about making decisions? What or who helps you make decisions?
    - i. What information do you rely on to make decisions?
    - ii. Do you seek help from anyone else?
    - iii. What, if any, conflicts arise?
    - iv. How are these resolved?
5. Perceived satisfaction/dissatisfaction of CR about decisions.
  - a. Tell me about how satisfied or dissatisfied you believe CR is about the decisions you make.
    - i. Can you give me an example of a time they were very satisfied or dissatisfied?
6. Financial Stress: How stressful is it for you to make financial decisions? On your own? With your CR?
  - a. How does this affect you?
  - b. How do you cope with this stress?
7. Financial context: How does your income play a role? How does CR's income play a role?
  - a. Tell me about your financial situation.
  - b. How does this impact the support you provide?

- c. How does this impact your decision-making?
- 8. Specific everyday proxy financial decision-making scenarios:
  - a. You mentioned BLANK was a financial decision you have made for or with CR, can you tell me about your process?
  - b. How do you go about making a decision?
  - c. What information do you use?
  - d. Who would you turn to for support? Why?
- 9. Formal plans/appointments.
  - a. Have there been any formal financial plans?
    - i. When were they set out and why (or not)?
    - ii. Have you sought out or received any support?
    - iii. What were the positive and negative consequences?
- 10. Option to discuss anything that we have not covered.

*\*adapted from Samsi & Manthorpe (2013)*

APPENDIX B

Telephone Screener

PARTICIPANT NAME: \_\_\_\_\_

PHONE: ( \_\_\_\_\_ ) \_\_\_\_\_

YOUR NAME \_\_\_\_\_ TODAY'S DATE: \_\_\_\_\_

Hello, may I speak with \_\_\_\_\_ *<respondent's name>* \_\_\_\_\_?

Hello Mr/Ms. \_\_\_\_\_, my name is \_\_\_\_\_ *<your name>* \_\_\_\_\_ and I'm calling from The Alabama Research Institute on Aging. You called our office recently about our caregiving study (**if cold call**, say you indicated you might be interested in ongoing research projects with our center). Do you remember seeing the flyer about the study (**if cold call, say**, would you still be interested in hearing about ways you can get involved?)?

**IF NO:** Well, this is study about women who are caring for a relative with Alzheimer's disease or other dementia. May I tell you a little more about it?

If you agree to participate, you will complete an interview with one of our project staff about your caregiving experiences. The interview asks about the kinds of financial decisions you make to help with caregiving and how you make them. The interview can take place at your home or another convenient place. It will last for about an hour to an hour and a half.

If your loved one who you care for is able and willing, they will also have to opportunity to answer some questions with a member of our project staff about the same kinds of topics.

For your participation in the interview we can offer you each a total of \$15 as well as two books that were meant to help caregivers like yourself.

Of course, the project is confidential and totally voluntary. It's your choice to participate or not, and if you do, we will work hard to protect your privacy. Do you have any questions?

Does this sound interesting to you?

**IF NO:** Well, thank you for your time. Have a good day! *<end call>*

**IF YES:** Great! Do you have about 15 minutes to talk and see if you are eligible to complete the study?

1. May I ask a few questions to see if you are eligible for the project?

- a. What is your age? \_\_\_\_\_
- b. Partner's age? \_\_\_\_\_
- c. Length of time married? \_\_\_\_\_
- d. CG highest level of education? \_\_\_\_\_
- e. CR highest level of education? \_\_\_\_\_

2. As you know, this is a study about caring for a spouse with memory problems. Do you provide care most days for a spouse aged 60 or older who has memory problems?

\_\_\_\_\_ YES                      \_\_\_\_\_ NO- Does not qualify; end call



<Probe for relationship/name of person with memory problems for use below>

3. What kinds of things do you help <CR> with?

*Check any items named; probe if items not mentioned.*

*To qualify for study, CG must help with **at least 3 IADLs (one must be managing finances)***

- |       |                          |        |   |
|-------|--------------------------|--------|---|
| ADLS: | _____ bathing            | IADLS: | _____ using the telephone                 |
|       | _____ dressing           |        | _____ transportation, getting around town |
|       | _____ grooming           |        | _____ shopping for groceries              |
|       | _____ eating             |        | _____ preparing meals                     |
|       | _____ toileting          |        | _____ housework                           |
|       | _____ bed/chair transfer |        | _____ home repairs, "handyman" work       |
|       | _____ mobility           |        | _____ laundry                             |
|       |                          |        | _____ managing medicines                  |
|       |                          |        | _____ <b>managing finances</b>            |

4. How recently did you begin helping them manage their finances? \_\_\_\_\_

*Does participant qualify?*    \_\_\_\_\_ YES    \_\_\_\_\_ NO - end call

5. Do you have any major health problems or serious illnesses that interfere with your ability to do the things you need to do? *(List medical conditions that exclude the participant. Things like hypertension, depression/anxiety, diabetes, obesity, etc. are fine.)*

6. These next questions may seem a little strange but I am required to ask them. I appreciate your patience. Please answer them to the best of your ability.

Response	Correct response	Check if <u>correct</u>
What are the date, month and year?		<input type="checkbox"/>
What is the day of the week?		<input type="checkbox"/>
What is your address?		<input type="checkbox"/>
What is your phone number?		<input type="checkbox"/>
How old are you?		<input type="checkbox"/>
When were you born?		<input type="checkbox"/>
Who is the current president?	Donald Trump	<input type="checkbox"/>
Who was the president before him?	Barack Obama	<input type="checkbox"/>
What was your mother's maiden name?		<input type="checkbox"/>
Can you count backward from 20 by 3's?	20-17-14-11-8-5-2	<input type="checkbox"/>
<b><u>SCORE:</u></b>		<i>(must score a 5 or greater)</i>

7. How financially stressful has caregiving been for you?

- Very Stressful
- Somewhat Stressful
- Not Stressful at all

8. How easy is it for you to pay for the very basics like food, housing, medical care, and heating?

- Not easy at all
- Somewhat easy
- Mostly easy
- Very easy

9. We are trying to include equal numbers of African American and White caregivers. So we can make sure we're doing that, would you mind telling me what race you consider yourself to be?

\_\_\_\_\_

10. We are also trying to include people with all types of income. So we can make sure we're doing that, would you mind telling me what you estimate your income to be?

\_\_\_\_\_

Does that include (care-recipient's name) income? \_\_\_YES \_\_\_NO

**IF CG DOES NOT MEET CRITERIA:** I'm sorry, I don't think our study is right for you. But we do appreciate your interest. Thank you so much for talking with me today.

**IF CG MEETS CRITERIA:** Great -- you are perfect for our study. Now I will just need to ask a few questions about (care recipient) so I can make sure they are also a good fit for our study.

**ADMINISTER ODRS**

If Score between 2 and 12, CR is eligible; if score >20, CR not eligible

**IF CR DOES NOT MEET CRITERIA:** Based on that description, we will not need to talk with (Care-Recipient's name); however, you are still a great fit for our study that requires a brief phone interview.

Would you like to set up a time to talk with one of our staff? There is a little paperwork to complete -- making sure that you understand the project and your rights as a research participant. That will take about 10 or 15 minutes, and then we could do the interview. Overall, it will take around one hour to one hour.

**IF CR AND CG MEET CRITERIA:** Great -- you are both perfect for our study. Do you have any questions for me at this point?

Would you like to set up a time to meet with one of our staff? There is a little paperwork to complete -- making sure that you understand the project and your rights as a research participant. That will take about 10 or 15 minutes, and then we could do the interview at that same visit. Overall it will take about one hour to one and half hours.

Where would you like to meet? We can come to your home, you can come to our offices at the University, or we can find another place that's convenient for you. What would you prefer?  
*If participant prefers her home/other location, be sure to get address!*

SUBJECT ID \_\_\_\_\_

DATE OF INTERVIEW: \_\_\_\_\_ TIME: \_\_\_\_\_

LOCATION OF INTERVIEW: \_\_\_\_\_

Based on address, is this participant rural or urban?

- Rural
- Urban

State

- Alabama
- NC

## APPENDIX C

### Quick Dementia Rating Scale (QDRS)

#### QUICK DEMENTIA RATING SYSTEM (QDRS)

The following descriptions characterize changes in the patient's cognitive and functional abilities. You are asked to compare the patient now to how they used to be – the key feature is **change**. Choose **one answer** for each category that best fits the patient – **NOTE**, not all descriptions need to be present to choose an answer

<b>1. MEMORY AND RECALL</b>	
0	No obvious memory loss or inconsistent forgetfulness that does not interfere with function in everyday activities
0.5	Consistent mild forgetfulness or partial recollection of events that may interfere with performing everyday activities; repeats questions/statements, misplaces items, forgets appointments
1	Mild to moderate memory loss; more noticeable for recent events; interferes with performing everyday activities
2	Moderate to severe memory loss; only highly learned information remembered; new information rapidly forgotten
3	Severe memory loss, almost impossible to recall new information; long-term memory may be affected
<b>2. ORIENTATION</b>	
0	Fully oriented to person, place, and time nearly all the time
0.5	Slight difficulty keeping track of time; may forget day or date more frequently than in the past
1	Mild to moderate difficulty keeping track of time and sequence of events; forgets month or year; oriented to familiar places but gets confused outside of familiar areas; gets lost or wanders
2	Moderate to severe difficulty, usually disoriented to time and place (familiar and unfamiliar); frequently dwells in past
3	Only oriented to their name, although may recognize family members
<b>3. DECISION MAKING AND PROBLEM SOLVING ABILITIES</b>	
0	Solves everyday problems without difficulty; handles personal business and financial matters well; decision-making abilities consistent with past performance
0.5	Slight impairment or takes longer to solve problems; trouble with abstract concepts; decisions still sound
1	Moderate difficulty with handling problems and making decisions; defers many decisions to others; social judgment and behavior may be slightly impaired; loss of insight
2	Severely impaired in handling problems, making only simple personal decisions; social judgment and behavior often impaired; lacks insight
3	Unable to make decisions or solve problems; others make nearly all decisions for patient
<b>4. ACTIVITIES OUTSIDE THE HOME</b>	
0	Independent in function at usual level of performance in profession, shopping, community and religious activities, volunteering, or social groups
0.5	Slight impairment in these activities compared to previous performance; slight change in driving skills; still able to handle emergency situations
1	Unable to function independently but still may attend and be engaged; appears "normal" to others; notable changes in driving skills; concern about ability to handle emergency situations
2	No pretense of independent function outside the home; appears well enough to be taken to activities outside the family home but generally needs to be accompanied
3	No independent function or activities; appear too ill to be taken to activities outside the home
<b>5. FUNCTION AT HOME AND HOBBY ACTIVITIES</b>	
0	Chores at home, hobbies and personal interests are well maintained compared to past performance
0.5	Slight impairment or less interest in these activities; trouble operating appliances (particularly new purchases)
1	Mild but definite impairment in home and hobby function; more difficult chores or tasks abandoned; more complicated hobbies and interests given up
2	Only simple chores preserved, very restricted interest in hobbies which are poorly maintained
3	No meaningful function in household chores or with prior hobbies



<b>6. TOILETING AND PERSONAL HYGEINE</b>	
0	Fully capable of self-care (dressing, grooming, washing, bathing, toileting)
0.5	Slight changes in abilities and attention to these activities
1	Needs prompting to complete these activities but may still complete independently
2	Requires some assistance in dressing, hygiene, keeping of personal items; occasionally incontinent
3	Requires significant help with personal care and hygiene; frequent incontinence
<b>7. BEHAVIOR AND PERSONALITY CHANGES</b>	
0	Socially appropriate behavior in public and private; no changes in personality
0.5	Questionable or very mild changes in behavior, personality, emotional control, appropriateness of choices
1	Mild changes in behavior or personality
2	Moderate behavior or personality changes, affects interactions with others; may be avoided by friends, neighbors, or distant relatives
3	Severe behavior or personality changes; making interactions with others often unpleasant or avoided
<b>8. LANGUAGE AND COMMUNICATION ABILITIES</b>	
0	No language difficulty or occasional word searching; reads and writes as well as in past
0.5	Consistent mild word finding difficulties, using descriptive terms or takes longer to get point across, mild problems with comprehension, decreased conversation; may affect reading and writing
1	Moderate word finding difficulty in speech, cannot name objects, marked reduction in word production; reduced comprehension, conversation, writing and/or reading
2	Moderate to severe impairments in speech production or comprehension; has difficulty communicating thoughts to others; limited ability to read or write
3	Severe deficits in language and communication; little to no understandable speech is produced
<b>9. MOOD</b>	
0	No changes in mood, interest or motivation level
0.5	Occasional sadness, depression, anxiety, nervousness or loss of interest/motivation
1	Daily mild issues with sadness, depression, anxiety, nervousness or loss of interest/motivation
2	Moderate issues with sadness, depression, anxiety, nervousness or loss of interest/motivation
3	Severe issues with sadness, depression, anxiety, nervousness or loss of interest/motivation
<b>10. ATTENTION AND CONCENTRATION</b>	
0	Normal attention, concentration and interaction with his/her environment and surroundings
0.5	Mild problems with attention, concentration, and interaction with environment and surroundings, may appear drowsy during day
1	Moderate problems with attention and concentration, may have staring spells or spend time with eyes closed, increased daytime sleepiness
2	Significant portion of the day is spent sleeping, not paying attention to environment, when having a conversation may say things that are illogical or not consistent with topic
3	Limited to no ability to pay attention to external environment or surroundings
<b>COGNITIVE SUBTOTAL (QUESTIONS 1, 2, 3, 8)</b>	
<b>BEHAVIORAL SUBTOTAL (QUESTIONS 4, 5, 6, 7, 9, 10)</b>	
<b>TOTAL QDRS SCORE</b>	

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## APPENDIX D

### Clinical Dementia Rating Scale (CDR)

#### Clinical Dementia Rating Questionnaire

This is a questionnaire which provides a basic set of questions to guide the interview. Please ask all of these questions. Ask any additional questions necessary to determine the patient's clinical dementia rating (CDR). Please note information from the additional questions.

##### Questions for the Informant (person close to the patient) about the Patient's Memory:

1. Does he/she have a problem with his/her memory or thinking?  Yes  No
- 1a. If yes, is this a regular problem (as opposed to irregular)?  Yes  No
2. Can he/she recall recent events?  Usually  Sometimes  Rarely
3. Can he/she remember a short list of items (shopping)?  Usually  Sometimes  Rarely
4. Has there been some worsening of memory during the past year?  Yes  No
5. Is his/her memory worsened to such a degree that it would have interfered with his/her activities of daily life a few years ago (or pre-retirement activities)? (informant's opinion)  Yes  No
6. Does he/she completely forget a major event (e.g., trip, celebration, family wedding) within a few weeks of the event?  Usually  Sometimes  Rarely
7. Does he/she forget relevant details of the major event?  Usually  Sometimes  Rarely
8. Does he/she completely forget important information of the distant past (e.g., birthdate, wedding date, workplace)?  Usually  Sometimes  Rarely
9. Tell me about some recent event in his/her life that he/she should remember. (For later testing, obtain details such as location of the event, time of day, participants, how long the event was, when it ended and how the patient or other participants got there).

Within 1 week:

---

Within 1 month:

---

10. When was he/she born? \_\_\_\_\_
11. Where was he/she born? \_\_\_\_\_
12. What was the last school he/she attended? \_\_\_\_\_  
Name \_\_\_\_\_  
Place \_\_\_\_\_  
Grade \_\_\_\_\_
13. What was his/her main occupation/job (or spouse's job if patient was not employed)? \_\_\_\_\_
14. What was his/her last major job (or spouse's job if patient was not employed)? \_\_\_\_\_
15. When did he/she (or spouse) retire and why? \_\_\_\_\_

**Questions for the Informant about Patient's Orientation:**

How often does he/she know of the exact:

1. Date of the Month?

Usually  Sometimes  Rarely  Don't Know

2. Month?

Usually  Sometimes  Rarely  Don't Know

3. Year?

Usually  Sometimes  Rarely  Don't Know

4. Day of the Week?

Usually  Sometimes  Rarely  Don't Know

5. Does he/she have difficulty with time relationships (when events happened in relation to each other)?

Usually  Sometimes  Rarely  Don't Know

6. Can he/she find his/her way in familiar streets?

Usually  Sometimes  Rarely  Don't Know

7. How often does he/she know how to get from one place to another outside his/her neighborhood?

Usually  Sometimes  Rarely  Don't Know

8. How often can he/she find his/her way around the house?

Usually  Sometimes  Rarely  Don't Know

## Clinical Dementia Rating Questionnaire

### Questions for the Informant about Patient's Judging and Problem Solving ability:

1. In general, if you had to rate his/her abilities to solve problems at the present time, would you consider them:

- As good as they have ever been?
- Good, but not as good as before?
- Fair?
- Poor?
- No ability at all?

2. Rate his/her ability to cope with small sums of money (e.g., make change, leave a small tip):

- No loss
- Some loss
- Severe loss

3. Rate his/her ability to maintain the expenses account of the household (e.g., balance check-book, pay bills):

- No loss
- Some loss
- Severe loss

4. Can he/she handle a household emergency (e.g., plumbing leak, small fire)?

- As well as before
- Worse than before because of trouble thinking
- Worse than before, another reason (why) \_\_\_\_\_

5. Can he/she understand situations or explanations?

- Usually
- Sometimes
- Rarely
- Don't Know

6. Does he/she behave\* appropriately [i.e., "the way he/she used to behave before the onset of his/her disease"] in social situations and interactions with other people?

- Usually
- Sometimes
- Rarely
- Don't Know

\*This item rates behaviour, not appearance.

## Clinical Dementia Rating Questionnaire

### Questions for the Informant about Patient's Outer Activities:

#### Occupational

1. Is the patient still working?  Yes  No  N/A  
 If not applicable, proceed to item 4  
 If yes, proceed to item 3  
 If no, proceed to item 2
2. Did memory or thinking problems contribute to the patient's decision to retire? (Question 4 is next)  Yes  No  D/K
3. Does the patient have significant difficulty in his/her job because of problems with memory or thinking?  
 Rarely or Never     Sometimes     Usually     Don't Know

#### Social

4. Did he/she ever drive a car/ a two wheeler?  Yes  No  
 Does the patient drive a car/ a two wheeler now?  Yes  No  
 If no, is this because of memory or thinking problems?  Yes  No
5. If he/she is still driving, are there problems or risks because of poor thinking?  Yes  No
- \*6. Is he/she able to independently shop for needs?  
 Rarely or Never (Needs to be accompanied on any shopping trip)     Sometimes (Shops for limited number of items; buys duplicate items or forgets needed items)     Usually     Don't Know
7. Is he/she able to independently carry out activities outside the home?  
 Rarely or Never (Generally unable to perform activities without help)     Sometimes (Limited and/or routine, e.g., superficial participation in religious activities or meetings; going to the beauty parlor / barber)     Usually (Meaningful participation in activities, e.g., voting)     Don't Know
8. Is he/she taken to social functions outside a family home?  Yes  No  
 If no, why not? \_\_\_\_\_
9. Would a casual observer of the patient's behavior think the patient was ill?  Yes  No
10. If in nursing home, does he/she participate well in social functions (thinking)?  Yes  No

#### IMPORTANT:

Is there enough information available to rate the patient's level of worsening in outer activities?

**If not, please probe further.**

Outer activities: Such as going to places of worship, visiting with friends or family, political activities, professional organizations such as associations of lawyers, other professional groups, social clubs, service organizations, educational programs.

\*Please add notes if needed to clarify patient's level of functioning in this area.

## Clinical Dementia Rating Questionnaire

### Questions for the Informant about Patient's Housework and Hobbies:

- 1a. What changes have occurred in his/her abilities to perform household tasks? \_\_\_\_\_  
\_\_\_\_\_
- 1b. What can he/she still do well? \_\_\_\_\_  
\_\_\_\_\_
- 2a. What changes have occurred in his/her abilities to perform hobbies? \_\_\_\_\_  
\_\_\_\_\_
- 2b. What can he/she still do well? \_\_\_\_\_  
\_\_\_\_\_
3. If in nursing home, what can he/she no longer do well (Housework and Hobbies)? \_\_\_\_\_  
\_\_\_\_\_

### Everyday Activities (Blessed Dementia scale):

- |                                       |              |     |                  |
|---------------------------------------|--------------|-----|------------------|
|                                       | No Worsening |     | Severe Worsening |
| 4. Ability to perform household tasks | 0            | 0.5 | 1                |

Please describe: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

5. Is he/she able to perform household tasks at the level of  
(Pick one. Informant does not need to be asked directly).

- No meaningful function?  
(Performs simple activities, such as making a bed, only with much supervision)
- Functions in limited activities only?  
(With some supervision, washes dishes with acceptable cleanliness; sets table)
- Functions independently in some activities?  
(Operates appliances, such as a stove/cooker; prepares simple meals)
- Functions in usual activities but not at usual level?
- Normal function in usual activities?

### IMPORTANT:

Is there enough information available to rate the patient's level of worsening in HOUSEWORK & HOBBIES?  
If not, please probe further.

Homemaking Tasks: Such as cooking, laundry, cleaning, grocery shopping, taking out garbage, yard work, simple maintenance, and basic home repair.

Hobbies: Sewing, painting, handicrafts, reading, entertaining, photography, gardening, going to theater or music concerts, woodworking, participation in sports.

Questions for the Informant about Patient's Personal Care:

\*What is your estimate of his/her mental ability in the following areas?

	Unaided	Occasionally buttons up wrongly, etc.	Wrong sequence commonly forgotten items (Forgets to wear underwear, etc)	Unable to dress
A. Dressing (Blessed Dementia Care)	0	1	2	3
	Unaided	Needs prompting	Sometimes needs help	Always or nearly always needs help
B. Washing, grooming	0	1	2	3
	Cleanly; proper utensils	Messily; spoon	Simple solids	Has to be fed completely
C. Eating habits	0	1	2	3
	Normal complete control	Occasionally wets bed	Frequently wets bed	Doubly uncontrollable
D. Control of bladder and bowel (Blessed Dementia Care)	0	1	2	3

Questions for the Patient about Memory:

1. Do you have problems with memory or thinking?  Yes  No
2. A few moments ago your (spouse, etc.) told me a few recent experiences you had. Will you tell me something about those? (Prompt for details, if needed such as location of the event, time of day, participants, how long the event was, when it ended and how the patient or other participants got there).

Within 1 week

1.0 – Largely correct \_\_\_\_\_  
 0.5 \_\_\_\_\_  
 0.0 – Largely incorrect \_\_\_\_\_

Within 1 month

1.0 – Largely correct \_\_\_\_\_  
 0.5 \_\_\_\_\_  
 0.0 – Largely incorrect \_\_\_\_\_

3. I will give you a name and address to remember for a few minutes. Repeat this name and address after me: (Repeat until the phrase is correctly repeated or to a maximum of three trials).

Elements	1	2	3	4	5
	Joseph	Raj,	42	Market Street,	Chennai
	Joseph	Raj,	42	Market Street,	Chennai
	Joseph	Raj,	42	Market Street,	Chennai

(Underline elements repeated correctly in each trial).

4. When were you born? \_\_\_\_\_
5. Where were you born? \_\_\_\_\_
6. What was the last school you attended?  
 Name \_\_\_\_\_  
 Place \_\_\_\_\_ Grade \_\_\_\_\_
7. What was your main occupation/ job (or spouse's if not employed)? \_\_\_\_\_
8. What was your last major job (or spouse's if not employed)? \_\_\_\_\_
9. When did you (or spouse) retire and why? \_\_\_\_\_

10. Repeat the name and address I asked you to remember:
- | Elements | 1      | 2    | 3  | 4              | 5       |
|----------|--------|------|----|----------------|---------|
|          | Joseph | Raj, | 42 | Market Street, | Chennai |

(Underline elements repeated correctly).



**Questions for the Patient about Orientation:**

Record the patient's answer word to word, for each question:

1. What is the date today?

Correct  Incorrect

---

2. What day of the week is it?

Correct  Incorrect

---

3. What is the month?

Correct  Incorrect

---

4. What is the year?

Correct  Incorrect

---

5. What is the name of this place?

Correct  Incorrect

---

6. What town or city are we in?

Correct  Incorrect

---

7. What time is it?

Correct  Incorrect

---

8. Does the patient know who the informant is (in your judgment)?

Correct  Incorrect

---

**Questions for the Patient about Judging and Problem Solving ability:**

Instructions: If initial response by patient does not merit a grade 0, press the matter to identify the patient's best understanding of the problem. Circle nearest response.

**Similarities:**

Example: "How are a pencil and a pen alike? (writing instruments)

How are these things alike? Patient's Response

1. turnip.....cauliflower \_\_\_\_\_  
(0 = vegetables)  
(1 = edible foods, living things, can be cooked, etc.)  
(2 = answers not relevant; differences; buy them)
2. desk.....bookcase \_\_\_\_\_  
(0 = furniture, office furniture; both hold books)  
(1 = wooden, legs)  
(2 = not relevant, differences)

**Differences:**

Example: "What is the difference between sugar and pickle? (sweet vs. sour)

What is the difference between these things?"

3. lie.....mistake \_\_\_\_\_  
(0 = one deliberate, one unintentional)  
(1 = one bad the other good - or explains only one)  
(2 = anything else, similarities)
4. river.....canal \_\_\_\_\_  
(0 = natural - artificial)  
(2 = anything else)

**Calculations:**

5. How many 5 paise in a rupee?  Correct  Incorrect
6. How many 25 paise in Rs.6.75?  Correct  Incorrect
7. Subtract 3 from 20 and keep subtracting 3 from each new number all the way down.  Correct  Incorrect

**Judgment:**

8. Upon arriving in a strange city, how would you locate a friend that you wished to see?  
(0 = try the telephone book, go to the municipality for a directory; call a mutual friend)  
(1 = call the police, call operator (usually will not give address))  
(2 = no clear response)
9. Patient's assessment of disability and social position and understanding of why he/she is present at the examination (even if it was already rated, give your personal opinion):  
 Good Insight  Partial Insight  Little Insight

CLINICAL DEMENTIA RATING (CDR)

CLINICAL DEMENTIA RATING (CDR):	0	0.5	1	2	3
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	Worsening				
	None 0	Questionable 0.5	Mild 1	Moderate 2	Severe 3
Memory	No memory loss or slight irregular forgetfulness	Regular slight forgetfulness; partial recollection of events; "harmless" forgetfulness	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss; only fragments remain
Orientation	Fully oriented	Fully oriented except for slight difficulty with time relationships	Moderate difficulty with time relationships; oriented for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disoriented to time, often to place	Oriented to self only
Judgment & Problem Solving ability	Solves everyday problems & handles business & financial affairs well; judgment good in relation to past performance	Slight worsening in solving problems, similarities, and differences	Moderate difficulty in handling problems, similarities, and differences; social judgment usually maintained	Severely worsened in handling problems, similarities, and differences; social judgment usually worsened	Unable to make judgments or solve problems
Outer activities	Independent function at usual level in job, shopping, volunteer and social groups	Slight worsening in these activities	Unable to function independently at these activities although may still be engaged in some; appears normal at casual glance	No pretense of independent function outside home Appears well enough to be taken to functions outside a family home	Appears too ill to be taken to functions outside a family home
Housework and Hobbies	Life at home, hobbies, and intellectual interests well maintained	Life at home, hobbies, and intellectual interests slightly worsened	Mild but definite worsening of function at home; more difficult tasks abandoned; more complicated hobbies and interests abandoned	Only simple tasks preserved; very restricted interests, poorly maintained	No significant function in home
Personal Care	Fully capable of self-care		Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; frequent loss of bladder and bowel control

Score only as worsening from previous usual level due to loss in memory or thinking, not worsening due to other factors.

## APPENDIX E

### IRB Approval



January 16, 2020

Keisha D. Carden, MA  
Department of Psychology  
College of Arts & Sciences  
The University of Alabama  
Box 870348

Re: IRB # 19-OR-027-R1 "More Money, More Problems?: A Grounded Theory of Financial Stress and Decision-Making among Dementia Caregiver-Care Recipient Dyads"

Dear Ms. Carden:

The University of Alabama Institutional Review Board has granted approval for your proposed research. Your renewal application has been given expedited approval according to 45 CFR part 46. Approval has been given under expedited review category 7 as outlined below:

*(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.*

The approval for your application will lapse on January 15, 2021. If your research will continue beyond this date, please submit a continuing review to the IRB as required by University policy before the lapse. Please note, any modifications made in research design, methodology, or procedures must be submitted to and approved by the IRB before implementation. Please submit a final report form when the study is complete.

Please use reproductions of the IRB approved stamped consent/assent forms to obtain consent from your participants.

Good luck with your research.

Sincerely,

[Redacted Signature]

Jessup Building | Box 870127 | Tuscaloosa, AL 35487-0127  
205-348-8461 | Fax 205-348-7189 | Toll Free 1-877-820-3066