

PREDICTORS AND MODERATORS OF MENTAL AND PHYSICAL HEALTH IN  
ELDERLY PARENTS OF ADULT OFFSPRING WITH SPECIAL NEEDS

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### Abstract

Many parents of adult offspring with intellectual and developmental disabilities or severe mental illnesses experience high levels of caregiver burden throughout their lives which may place them at high risk for deleterious consequences in old age. Research suggests that interpersonal and intrapersonal resources may buffer the negative effects of burden for these parents. Using data from the Wisconsin Longitudinal Study (WLS), the current study examined the memory functioning, health related quality of life, and depressive symptoms of parents of adult offspring with disabilities or long-term mental illnesses and the potential buffering effects interpersonal and intrapersonal resources on the effects of caregiver burden. Differences between the disability groups and resident status were also examined. The results showed few differences between the groups in the functioning and resource variables, suggesting similarities not seen in earlier years. The hypotheses that greater self-reported caregiver burden would significantly predict poorer health related quality of life and more depressive symptoms, and that psychological well-being would be positively associated with positive functioning across all domains were supported. However, findings related to social participation were inconsistent as few forms of social participation buffered the effects of caregiver burden on functioning in old age. Follow up analyses revealed that organization participation was most impactful only under certain circumstances, as its impact was either enhanced or reversed depending on the person's level of perceived burden. Implications for intervention are discussed.

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## Introduction

Previous research has shown that social participation is an important buffer against depression for aging parents of children with intellectual and developmental disabilities. A study by Olsen, Floyd, Mailick, & Greenberg (2018) found that parents of children with disabilities generally experience higher rates of depressive symptoms than matched control parents of typically developing children, consistent with previous research using the same sample (Seltzer, Floyd, Song, Greenberg, & Hong, 2011). The study also examined whether low levels of social participation would account, at least in part, for high levels of depressive symptoms among all older parents, and particularly for parents of children with disabilities and those who co-reside with the child. The study found that continued co-residence with an adult child with intellectual and developmental disabilities in early old age (i.e., early 60s) moderated the relationship between social participation and depression. Specifically, high levels of participation with family members were associated with relatively low levels of depressive symptoms in parents co-residing with their children with disabilities. These findings suggest that social participation with family members may be a critically important interpersonal resource for these parents, at a time when they are particularly vulnerable to high rates of depressive symptoms.

### Present Study

The purpose of the present study was to extend our understanding of the effects of lifelong stress in aging parents. It expands on the previous study by focusing on the period of time when the parents have reached old age (early 70s), approximately seven years after the data for the previous study were collected. Recent research has examined parents of children with disabilities in early old age (mid-60s) (Seltzer et al., 2011), yet very little research has focused exclusively on parents in their 70s. For most adults, old age is a time when parents transition from caregiver to care recipient. Yet, many parents of children with disabilities continue to provide care to their adult child, possibly putting these parents at high risk for deleterious consequences. Thus, a cross-sectional design was used to focus on the years in which parents are potentially experiencing the most severe effects of life-long caring for their adult offspring.

The current study also expands on the findings of the previous study by including parents of children with severe, long-term mental illnesses in addition to parents of children with developmental disabilities. Previous research has examined the differences between the groups in

midlife and early old age. The studies found that parents of adult children with mental illness have greater levels of caregiver burden (Seltzer, Greenberg, Floyd, & Hong, 2004), poorer self-reported health (Magaña, Greenberg, & Seltzer, 2004), and poorer psychological functioning (Ghosh, Greenberg, & Seltzer, 2012) in midlife and early old age compared to parents of children with disabilities and typically developing children. Yet at the time of this writing, there are no known studies that have examined the differences between these groups in their 70s (old age). Further, older age may increase vulnerability to chronic stress for both sets of parents which may lead to even larger discrepancies between the groups. Thus, examining group differences in old age is an important next step to determine if the findings of previous studies hold as the parents continue to age. Many of the measures used in the current study were only obtained for parents of offspring with disabilities or mental illness given that they are not relevant to typically developing children, thus a normative group was not used in the current study due to lack of available data.

The current study also expands on the previous study by adding a continuous measure of the extent to which a parent is burdened by raising their child, rather than simply using the condition of parenting of a child with a disability as a blanket indicator of stress. A continuous measure assesses variations in the experiences of stress for these parents. The previous study examined parenting stress by contrasting the disability group with a putatively normative comparison group. In that study, having a child with a disability was used as a gross measure of stress that is not sensitive to variations in degrees of stress experienced by parents of children with disabilities. Contrary to the previous study, all parents in the current study have a child with special needs (i.e., disability, severe long-term mental illness). The distinguishing characteristics between the groups is disability type rather than existence of a disability, and amount of caregiving stress. Thus, the current study evaluates within-group variations by using a continuous measure of stress that is specific to caring for a child with special needs.

Further, the current study extends the findings of the previous study by examining parents' functioning across multiple domains. Though depressive symptoms remain highly relevant and important in old age, caregiver burden may affect parents in more ways than high depressive symptoms. Specifically, chronic stress is associated with low memory and physical functioning in old age, especially in parents of children with disabilities and severe, long-term



mental illnesses (Marin, Lord, Andrews, Juster, Sindi, Arsenauly-Lapierre, Fiocco, & Lupien, 2011; Brehaut et al., 2004). An examination of these other domains of functioning may shed light on the other ways that lifelong chronic stress affects the body and mind, and will allow for more encompassing conclusions about the effects of raising children with disabilities or severe, long-term mental illnesses. As such, the current study examines three domains of functioning in old age including concurrent health related quality of life, memory functioning, and depressive symptoms.

Lastly, the current study expands on the previous study's finding that social participation buffers the effects of stress on depressive symptoms by examining both social participation as an interpersonal resource, and psychological well-being as an intrapersonal resource. Specifically, psychological well-being may represent a vital resource that exists within the individual that may diminish the effects of stress by allowing the individual to learn and grow despite the challenges they face, while maintaining self-esteem and optimal functioning. Over time, maintaining well-being from within may guard against the potential wear and tear associated with lifelong chronic stress that has been shown to result in high depressive symptoms (Pearlin, 1989). Psychological well-being has been associated with life satisfaction, affect balance, and self-esteem (Ryff, 1989b). Thus, it is important to learn if psychological well-being can also act as a buffer of stress for chronically stressed parents, in order to better understand potential sources of resiliency for parents.

### Parental Stress

Raising children with intellectual and developmental disabilities is often associated with high levels of stress for the parents. Studies have shown that parents of children with disabilities experience higher levels of parenting stress than parents of typically developing children (Dumas, Wolf, Fisman, & Culligan, 1991). Further, studies have shown that stress associated with child rearing is experienced on a greater number of days for these parents than for parents of typically developing children (Seltzer, Almeida, Greenberg, Savla, Stawski, Hong, & Taylor, 2009). Sharpley, Bitsika, and Efremidis (1997), found that more than 80% of parents of children with autism spectrum disorder reported sometimes being "stretched beyond their limits", meaning that they felt their tasks outweighed their ability to complete them. Further, Schieve, Blumberg, Rice, Visser, and Boyle (2007) found that parents of children with developmental

disability may feel more frustrated and even aggravated by the day to day stress that is placed on them than parents of typically developing children, presumably because the ongoing childrearing stress makes other stressors less tolerable.

There are many unique sources of stress that parents of children with disabilities experience that may be more pronounced than those experienced by parents of typically developing children. One source of stress comes directly from high levels of care taking demands that are not experienced by parents of children with typically developing children (Dumas et al., 1991). Plant and Sanders (2007) found that difficulties of performing caregiving tasks and managing difficult child behavior during care-taking tasks are the primary factors that contribute to the unique stress of parents of children with disabilities. Children with intellectual and developmental disabilities also frequently exhibit high levels of behavioral difficulties such as sleep problems (Allik, Larsson, & Smedje, 2006), emotional problems (Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006), and other challenging behaviors (Abbeduto et al., 2004) which may constitute additional sources of stress for the parents. Children with certain developmental disabilities also experience deficits in adaptive behaviors such as getting dressed or taking public transit that may increase caretaking demands and contribute to parental stress (Bishop, Richler, Cain, & Lord, 2007). Abbeduto and colleagues (2004) found that the extent and severity of these difficulties are predictors of poor well-being for mothers. Further, the negative impacts of high stress on the parents have been found to persist into the parents' old age, after the child has reached adulthood (Ha, Hong, Seltzer, & Greenberg, 2008; Miodrag & Hodapp, 2010).

Raising a child with a disability may have practical ramifications that impact the entire family, thus leading to high levels of stress. In a study comparing children with comorbid autism spectrum disorder (ASD) and intellectual disability (ID), Saunders, Tilford, Fussell, Schulz, Casey, and Kuo (2015) found that more than half of caregivers of children with ASD and ID reported financial difficulties (52%). The study also found that around 51% of the parents of children with disabilities had to stop work to care for the child and more than one third of caregivers of children with intellectual or developmental disabilities reported having at least \$1,000 out of pocket costs to provide care for children within the year before the study.

Parents of adult children with severe, long-term mental illness, such as schizophrenia and bipolar disorder, experience stress across the life course similar to parents of children with intellectual and developmental disabilities. Though there is data to suggest that individuals diagnosed with bipolar disorder at a young age may be symptom free or experience only subclinical symptoms later in life (Lewinsohn, Klein, & Seeley, 1995, 2000) the stress comes over many years of the parents providing extended care to their child during times when the symptoms of their child's mental illness produce ongoing obstacles to social and occupational functioning and independent living (Mueser & McGurk, 2004). Further, with the onset of the illness, parents may struggle emotionally with the diminished expectations and experience feelings of loss (Miller, Dworkin, Ward, & Barone, 1990). These feelings of loss may be exacerbated when parents must put their own personal needs and plans on hold in order to meet the growing needs of the adult child (Cook & Cohler, 1986; Leventhal, Leventhal, & Nguyen, 1985). Further, parents of children with severe, long-term mental illnesses may feel shame and embarrassment when their child does not achieve expected life course goals, such as marrying or raising children, at a time when same-age peers have already accomplished those same goals (Goldstein & Kreisman, 1988).

Coping with the stress generated by the challenges of raising children with SMI have been found to lead to psychological strain including shame, grief, frustration, anger, and anxiety (Grandón, Jenaro, & Lemos, 2008). Parents may also frequently feel concern about the well-being of their child with severe, long-term mental illnesses. Specifically, parents may be concerned about their child's day-to-day functioning and safety, and may feel uneasy or anxious about future care of the child (Francell, Conn, & Gray, 1988; Lefley, 1987). This comes at a time when older parents become increasingly concerned about the future care of their children with severe, long-term mental illness after the parent passes away (Hatfeild & Lefley, 2005). Further, parents of children with severe, long-term mental illness in old age have compounding stress of coping with the challenges of having an adult child with serious mental illness while simultaneously adjusting to their own aging-related changes in health, such as physical disability and greater vulnerability to illness (Biegel & Schulz, 1999; Lefley, 2003).

## Caregiver Burden

Despite the extensive literature on stress in parents of children with disabilities and severe, long-term mental illnesses, parent's experiences often differ across different people which may be indicative of differences in parental caregiver burden. According to Adelman Tmanova, Delgado, Dion, and Lachs (2014), the act of caregiving is assisting another person with both basic and instrumental activities of daily living, giving medical support (e.g., medication management, scheduling/accompanying to medical visits, and making treatment/management decisions), as well as providing emotional support and comfort to the care recipient. Caregiver burden has been described as the extent to which caregivers perceive that their emotional, social, financial, physical, and spiritual functioning has been negatively affected by giving care (Zarit, Todd, & Zarit, 1986). Zarit, Reeve, and Bach-Peterson (1980) suggested that embarrassment, overload, feelings of entrapment, and resentment are also included in the construct of caregiver burden, while Morris, Morris, and Britton (1988) also added loss of control and poor communication to the definition.

Caregiver burden can be separated into two components: subjective and objective burden. Objective burden is generally defined as the routine limitations on the quality of social, occupational, and familial domains (Pickett, Greenley, & Greenberg, 1995) indicating an observable and quantifiable form of burden. For parents of children with disabilities and severe, long-term mental illnesses, objective burden may be the amount of time the parents dedicate to caring for their child which could otherwise be used for other activities. In contrast, subjective burden generally refers to self-reported psychological reactions to the objective burden (Magliano, Fadden, Madianos, de Almeida, Held, & Guarneri, 1998). In parents of children with disabilities or severe, long-term mental illnesses, subjective burden may come in the form feeling that their child is fully dependent on them or feelings of discomfort when having friends or family over due to the behaviors of their child. Both forms of burden are distinct and important to understanding the full spectrum of burden experienced by the individual.

The effects of caregiver burden are widespread. The National Alliance for Caregiving and the American Association of Retired Persons (2015) recently conducted a national survey on a normative sample of caregivers including those caring for persons with short-term physical conditions, long-term physical conditions, emotional/mental health issues, behavioral issues,

developmental or intellectual delays, or memory problems. As an objective measure of burden, the survey found that caregivers spend an average of 24.4 hours per week providing care. As a subjective measure, of the individuals providing care, 40% of them reported experiencing high levels of burden, while 18% reported moderate levels of burden, and 41% reported relatively low burden based on time spent providing care and how dependent the recipient was on the caregiving. Also, as a subjective measure of burden, the survey also found that 38% of caregivers consider their caregiving situation to be emotionally stressful, including 53% of those caring for someone with a mental health issue. Research has also shown that both forms of burden continue unabated over time, with Herz, Endicott, and Spitzer (1976) finding that burden within the family remains steady even after the ill family member improves.

The effects of caregiver burden may be especially profound for parents of children with disabilities or severe, long-term mental illnesses. A review by Adelman, Tmanova, Delgado, Dion, and Lachs (2014) showed that caregivers who spend a high number of hours caregiving are the most likely to report high levels of burden. Further, the National Alliance for Caregiving and AARP (2015) survey found that caring for an individual with emotional, behavioral, or mental health issues or developmental or intellectual delays are some of the strongest risk factors for high levels of caregiver burden. These findings indicate that parent caregivers of children with disabilities or severe, long-term mental illnesses may be at greater risk of experiencing caregiver burden than parents who have not experienced chronic stress. Other studies have found that caregivers who assist care recipients with activities of daily living and those who care for persons with behavioral problems, both of which are common for parents of children with disabilities and children with severe, long-term mental illness, exhibit greater burden than caregivers who assist with other care needs (Gottlieb, Burleson, Kloner, Babior, & Engler, 1994).

The effects of caregiver burden may now also be lasting longer for parents of children with disabilities and severe, long-term mental illness because of increases in the life expectancy for these individuals (Hennekens, Hennekens, & Hollar, 2005; Janicki, Dalton, & Henderson, 1999). Many parents continue to live with their child into retirement age. Specifically, the previous study found that 37.2 percent of the children with intellectual and developmental disabilities lived at home while the parents were in their 60s (Olsen et al., 2018). Other studies

have found that in the United States, up to 76 percent of older adults with intellectual disability live in the home with their families. That estimate coincides with the approximately 1.7 million adults with intellectual and developmental disabilities that are supported by older and middle-age family caregivers (Braddock, Hemp, Rizzolo, Coulter, Haffer, & Thompson, 2008).

### Co-Residence

Remaining in the same residence as the care recipient has been shown to have deleterious effects on the caregiver. It has been found that caregivers who live with the person they are caring for experience greater caregiver burden than those who live in a separate location (Gottlieb, Burleson, Kloner, Babior, & Engler 1994). More specifically, Brodaty and Hadzi-Pavlovic (1990) found that caregivers who lived in the home with the care recipient experienced worse physical health than caregivers who lived in separate locations. These research findings indicate that continued co-residence represents a risk factor for poorer functioning when the caregiver enters old age.

Accordingly, co-resident status has been shown to be an important distinguishing characteristic in the current sample. Seltzer et al. (2011) used co-resident status to examine differences in parents of adolescents and adults with intellectual and developmental disabilities. The study found that in the early years of old age, parents co-residing with their adult children had significantly higher levels of depression relative to a comparison group of parents with typically developing children. Olsen et al. (2018) also found co-resident status to be an important variable. The study found that parents of children with intellectual and developmental disabilities in old age were most vulnerable to the deleterious effects of low socialization with family if they were co-residing with their adult child.

### Physical Health

In light of the literature demonstrating that parents of children with disabilities and long-term illnesses experience stress and caregiver burden which can be exacerbated by continued co-residence, new questions arise about potential long-term consequences. One potential long-term consequence of caregiver stress and burden is compromised physical functioning in old age. In the caregiving literature, the caregivers themselves are sometimes referred to as the “hidden patients” of the caregiving dyad given the frequent isolation, loneliness, economic hardship, and

role overload that caregivers experience (Fengler & Goodrich, 1979). These “hidden patients” often experience adverse health consequences. Schulz, O’Brien, Bookwala, and Fleissner (1995) found that between 18% and 35% of caregivers of persons with dementia perceive their health as fair or poor. Pinquart and Sorensen (2003) found that informal caregivers, those who are not compensated, have poorer perceived physical health than non-caregivers, while Vitaliano, Zhang, and Scanlan (2003) found that these caregivers have poor health based on physiological measures. As such, caregiver stress and burden may lead to compromised physical functioning in old age.

The effects of caregiver burden may be particularly difficult for parents of children with special needs due to the ongoing buildup of stress associated with the extreme length of caregiver burden, in contrast to most caregiving situations which are relatively short term. A recent national survey on caregiver burden found that the longer a caregiver has been providing care, the more likely she or he is to report fair or poor health (National Alliance for Caregiving, 2015). Research has shown that in later life (e.g., retirement years), parents caring for children with developmental disabilities are at greater risk of experiencing health declines than their peers without similar caregiving responsibilities (Seltzer et al., 2011). Brehaut et al. (2004) found that parents of children with chronic health problems had a greater number of chronic diseases, sight problems, and hearing problems, as well as more physical pain than other parents. Yamaki, Hsieh, and Heller (2009) found that mother and sister caregivers of adults with intellectual and developmental disabilities had high levels of arthritis, high blood pressure, obesity, and activity limitations in midlife and early old age compared to women in the general population. Specifically, daily activities such as lifting groceries, climbing stairs, and walking distances were nearly twice as limited for older caregivers than for those in the general population. It appears that the physical effects of caring for an adult with a disability increases over time. The study also found that, compared to midlife caregivers, older caregivers had: 2.0 times higher incidence of arthritis, 1.8 times higher blood pressure, 3.5 times higher incidence of osteoporosis, and 2.5 times higher activity limitations. The caregivers in late life also reported a greater number of unhealthy days (4.31) than the caregivers in midlife (2.18) (Yamaki et al., 2009). Burton, Lethbridge, and Phipps (2008) found a negative relationship between the mother’s self-reported health and parenting a child with a severe disability, especially if the disability persisted over many years. As such, it is expected that elderly parents of children with disabilities and severe,

long-term mental illnesses, who presumably have been caring for their children for many years, would have low levels of physical functioning especially if they still are co-residing with the child.

Though there are many ways of measuring an individual's physical health, a sensitive and psychometrically sound measure that has been used extensively in aging research is health related quality of life (HRQoL). According to the Centers for Disease Control's (CDC) most recent definition of HRQoL, it is an individual's "physical and mental health perceptions (e.g., energy level, mood) and their correlates—including health risks and conditions, functional status, social support, and socioeconomic status." (Centers of Disease Control and Prevention, 2000). The CDC also states that HRQoL is widely considered to be a valid indicator of unmet needs, and is an important component of surveilling public health (Centers of Disease Control and Prevention). Donohue (2002) demonstrated that the construct of HRQoL synthesizes both the concepts of health status and quality of life, both of which can be compromised by lifelong caring for individuals with disabilities and severe, long-term mental illnesses, making it a highly relevant and appropriate measure to use on this population.

### Cognitive Functioning

In addition to loss of physical functioning, a growing body of literature indicates that chronic stress and burden may lead to cognitive deficits in people as they reach old age (Marin et al., 2011). The most consistent cognitive deficit chronically stressed individuals face is impairment to memory functioning. Specifically, Lupien and McEwen (1997) found an inverted-u-shaped relationship between stress indicators (e.g., cortisol levels) and memory performance. In laboratory studies on individuals across the lifespan (i.e., children, adolescents, elderly) Lupien, Fiocco, Wan, Maheu, Lord, Schramek, and Thanh Tu (2005) found that individuals with higher stress hormones (i.e., glucocorticoid elevations which is a nonspecific indicator of chronic stress) were found to experience impairments in the retrieval of information. These findings were supported by Cavanagh, Frank, and Allen (2011) who also found that stress leads to diminished cognitive functioning in laboratory studies. McEwen (2003) demonstrated that stress in early life can result in structural changes in both the amygdala and hippocampus which are important areas in the brain that influence memory. The structural changes continue to develop over time leading to increasingly diminished memory functioning when the stressor is chronic, much like the stress



that parents in this study face. In old age, sex differences have been found in cognitive abilities. Specifically, Munro et al (2012) found that women had higher scores on tests of psychomotor speed and verbal learning and memory. However, the same study found that elderly men between the ages of 67 and 88 years had higher scores on tasks of visuoconstruction and visual perception tasks, thus sex differences are unclear.

These findings are directly applicable to parents of children with disabilities and severe, long-term mental illnesses given that they have been shown to experience more memory difficulties than parents of typically developing children. Specifically, Brehaut et al. (2004) examined parent caregivers of children with disabilities and found that these parents experienced more memory problems (i.e., difficulty with memory or problem solving) compared to a sample of parents with typically developing children. Other research has also found elevated daily cortisol levels these parents on days when the parents spent the most time with their children (Seltzer et al., 2009). Thus, diminished memory functioning may be especially relevant for individuals that have experienced long term parenting stress.

### Psychological Functioning

Psychological functioning (principally in the form of depressive symptoms) is also likely to be compromised when caregivers are faced with ongoing stress. In caregivers of individuals with dementia, the prevalence of depressive symptoms is as high as 43% to 47%. (Livingston, Manela, & Katona, 1996; Waite, Bebbington, Skelton-Robinson, & Orrell, 2004). Studies of parent, child and relative caregivers of various chronic conditions (e.g., dementia, disability) have shown that general caregiver burden, is associated with high levels of depressive symptoms (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). Further, research has found that, in general, the incidence rate of depressive symptoms in parents of children with disabilities may be up to three times higher than in the general population (Resch, Elliott, & Benz, 2012). Other studies have also demonstrated that 24 to 36 percent of the parents of children with disabilities may experience high levels of depressive symptoms, representing a significantly higher prevalence rate compared to the general population (Bailey, Golden, Roberts, & Ford, 2007; White & Hastings, 2004).

Psychological functioning may be particularly diminished in parents of children with disabilities and severe, long-term mental illnesses, given the research showing that there are

many emotional stresses and psychological strains that persist over the life course for these parents (Greenberg, Seltzer, & Greenley, 1993; Seltzer, Greenberg, & Krauss, 1995). Brehaut et al. (2004) also found that parents of children with chronic health problems had higher levels of distress, chronicity of distress, and higher emotional problems than the general population of caregivers. Other research has shown that adolescents with traumatic brain injury exhibit high levels of externalizing behavior problems, which are associated with poor overall psychological functioning (e.g., depression, anxiety, somatization) and symptoms of psychopathology for parents (Raj, Wade, Cassedy, Taylor, Stancin, Brown, & Kirkwood, 2013). Other studies have demonstrated that maternal psychological well-being improves when an adolescent or adult child with an ASD moves out of the family home (Greenberg, Seltzer, Krauss, & Kim, 1997; Krauss, Seltzer, & Jacobson, 2005; Seltzer, Greenberg, Krauss, & Hong, 1997). As such, it is expected that parents who care for children with disabilities or severe, long-term mental illnesses over their lifespan are likely to experience high levels of psychological distress in the form of depressive symptoms.

#### Interpersonal Factors

Despite the negative impacts parenting children with disabilities or severe, long-term mental illnesses can have, parents may have interpersonal protective factors to buffer the effects of stress. Specifically, social participation, which involves how frequently and actively a person engages in formal and informal groups and other social activities (Hyppa, Maki, Alanen, & Impivaara, 2008) has been found to be frequently disrupted for parents of children with disabilities throughout their lives (Murray, 2007; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). Olsen et al. (2018) found that both participation with friends and participation in organizations were associated with lower levels of depression in old age, both for parents of children with disabilities and for parents of typically developing children. The study also found that social participation acted as a protective factor against depression for parents co-residing with their adult children with disabilities. Thus, contact with family was particularly important for parents living with children with disabilities in early old age suggesting that family contacts might play a unique role in managing stress for these parents.

## Social Participation

Social participation can be separated into formal and informal social participation. Informal social participation involves voluntary social encounters in the community that lack structure within a larger organization. These interactions generally benefit one's own development and well-being (Groenou & Deeg, 2010). Ritchey, Ritchey, and Dietz (2001) found that the number of visits with friends was strongly related to overall well-being in older adults. Ties to friends can also provide companionship and emotional support to the recipient (Lapierre & Keating, 2013), which may in turn reduce stress and depression. Further, participation with friends may be particularly relevant to aging parents of children with disabilities or severe, long-term mental illnesses given that friendship ties and are often especially rewarding to older adults (Litwin, 2001). Also, time spent seeing family and friends has been found to be positively associated with happiness (Lelkes, 2006; Powdthavee, 2008). Other studies have demonstrated the importance of contact with family, as having relatives that are emotionally close has also been found to be positively related to happiness (Leung, Kier, Fung, Fung, & Sproule, 2013). Serovich, Kimberly, Mosack, and Lewis (2001) found that perceived family support predicts lower levels of loneliness, stress, and depressive symptoms in at-risk populations. As such, both participation with friends and family members are important interpersonal resources that aging parents may possess to buffer the effects of stress and caregiver burden in late life.

Formal social participation is a form of socializing where a person is engaged in structured interactions with others within a larger organization in the community. These interactions generally come through involvement in groups or clubs (Groenou & Deeg, 2010). Research on formal social participation has shown that participation in organized clubs and other associations was predictive of greater well-being for elderly adults (Veenstra, 2000). Similarly, Van Willigen (2000) found that obligations to groups were predictive of greater well-being for elderly adults. These findings highlight the importance of using formal social participation activities in addition to informal participation to gain a comprehensive look at interpersonal resources.

There is also considerable research describing the mechanisms by which social isolation, and conversely social participation, can influence the lives of people entering old age. Low levels of social participation may limit access to resources such as aid, information, and emotional

support, which are important for emotional well-being in old age (Kawachi, Kennedy, & Glass, 1999). In contrast, those who experience high levels of social participation may have access to greater emotional support and connection to the greater community, allowing more opportunities to become aware of helpful resources that could promote positive functioning and well-being (Liebler & Sandefur, 2002). Also, social support may reduce stress by promoting cognitive reappraisals that reduce the emotional impact of stressful situations (Lazarus & Folkman, 1984). Social interactions with family, groups, or community may lead to social integration that promotes a sense of belonging and establishes or maintains positive interpersonal attachments (Hagerty, Williams, Coyne, & Early, 1996). Friendship ties provide both emotional support and companionship, both of which are important for well-being of individuals in old age (Lapierre & Keating, 2013). Further, Cornwell and Laumann (2015) found that declines in self-rated health and increased functional impairment were associated with the loss of confidants over a 5-year period.

In older adults, social participation has been found to be associated with overall positive affect (Everard, Lach, Fisher, & Baum, 2000) and fewer depressive symptoms (Chou & Chi, 2003). Research has shown that older adults with a greater frequency of contact with others may also experience lower levels of depressive symptoms in the future (Glass, De Leon, Bassuk, & Berkman 2006; Law & Sbarra, 2009). Conversely, having a limited social network has been significantly associated with depressive symptoms in older adults (Tsai, Yeh, & Tsai, 2005; Luppá, Sikorski, Luck, Weyerer, Villringer, König, & Riedel-Heller, 2012). Thus, interpersonal resources are important for continued positive psychological functioning in old age.

### Psychological Well-Being

In addition to interpersonal resources for coping with chronic stress, other intrapersonal factors might also promote successful adaptation over time. Intrapersonal resources are strengths that exist with the individual such as positive outlooks and command over one's life regardless of obstacles the person may face. They may buffer the effects of stress by bolstering a person's resilience from within. Notably, in developing a measure to identify intrapersonal resources, Ryff (1989a) focused on six domains that might contribute to successful coping: self-acceptance, positive relations to others, autonomy, environmental mastery, purpose in life, and personal growth. Each of the dimensions of the Scales of Psychological Well-Being articulate different

challenges individuals encounter as they strive to function positively (Ryff, 1989a; Ryff & Keyes, 1995). High scores on each of the scales indicate distinct positive resources within the individual that may make the person more resilient in the face of stress throughout life. Specifically, the self-acceptance scale measures the individual's attitude toward his or her current and past life as well as their attempts to feel good about themselves while remaining aware of their own limitations. The positive relations with others scale measures the extent to which an individual has high quality, satisfying relationships with others while seeking to develop and maintain more warm and trusting interpersonal relationships. The environmental mastery scale measures how much a person is able to shape their own environment to meet his or her personal needs and desires. The autonomy scale measures an individual's sense of self-determination, independence, freedom from norms, individuality, self-determination, and personal authority. The purpose in life scale measures the extent to which the person believes that his or her own life is meaningful, and the ability to find meaning in one's personal efforts and challenges. The personal growth scale measures how much a person makes the most of his or her own talents and capacities while remaining open to new experiences (Ryff, 1989a; Keyes, 2002). Taken together, the total of all scales of psychological well-being offer a comprehensive look at many aspects of intrapersonal resources a person possess that may be used to buffer the effects of stress.

The Scales of Psychological Well-Being have been a useful tool in studies of aging populations. In a study of changes in well-being associated with aging, Ryff (1989b) found that environmental mastery and autonomy, increased with age, particularly from young adulthood to midlife whereas personal growth and purpose in life, decreased. The study also found that positive relations with others and self-acceptance, did not change over time. In a study of bereaved parents, Floyd, Seltzer, Greenberg, and Song (2013) found that the purpose in life subscale remained stable over time. The study also found that a parent's sense of purpose in life before the child's death and over time were associated with improvements in functioning, especially for those whose child died unexpectedly. These findings were consistent with Rogers, Floyd, Seltzer, Greenberg, and Hong (2008), which found that bereaved parents who had or were able to find a purpose in their own lives after their child's death were better adjusted than parents who did not have a sense of purpose in life. Major reviews have also documented the link

between poor psychological well-being and compromised health, including cardiovascular risk, morbidity, and mortality (Pressman & Cohen, 2005; Boehm & Kubzansky, 2012).

The Ryff Scales of Psychological Well-Being have also been used in disability and mental illness research. Esbensen, Mailick, and Silverman (2013) used the Ryff Scales to examine parents of aging adults with intellectual and developmental disabilities. They found that higher initial levels and later improvements in positive psychological well-being of the parents predicted better physical health of the child in later life. Also, Rogers et al. (2008) used the Ryff Scales to show that parents of children who passed away experienced lower levels of well-being later in life, indicating chronic strain associated with bereavement. Thus, intrapersonal resources, measured by the Ryff Scales of Psychological Well-Being, are likely to be an important buffer of stress and burden in parent of children with disabilities and severe, long-term mental illnesses in old age.

#### Sex Differences

The effects of stress for parents of children with developmental disabilities and long-term, severe mental illness may differ for mothers and fathers. Olsen et al. (2018) found sex differences in rates of depressive symptoms in parents of children with disabilities in old age, with mothers reporting high rates of depressive symptoms. Seltzer et al. (2011) found sex difference in number of organizations, frequency of friend and family participation, and depressive symptoms in parents of children with disabilities in midlife and old age. However, the study did not find significant sex differences in psychological well-being or health related quality of life in either time point. The findings may be indicative of more traditional gender roles that exist in families who have children with intellectual and developmental disabilities (e.g., Crnic, Arbona, Baker, & Blacher, 2009; Floyd & Gallagher 1997; Parish, Seltzer, Greenberg, & Floyd, 2004). As such, gender effects may be an important factor in understanding the experiences of parents with children with disabilities and severe, long-term mental illnesses in old age.

#### The Current Study

The current study follows up on a previous study that examined social participation (friend, family, and organization) in the early child rearing years, midlife, and early old age as possible mediating variables between having a child with a developmental disability and

depression in midlife and early old age. The results of the study showed that social participation did not mediate the relationship between child-related stress and depression. Instead, social participation had a separate main effect on reducing depression across multiple time points. Furthermore, family participation in particular was most important for reducing depression for the parents who co-resided in early old age with children with intellectual and developmental disabilities (Olsen et al., 2018).

As noted above, parents of children with severe, long-term mental illness also experience stress and caregiver burden. Similar to parents of children with developmental disabilities, the stress and burden may be particularly deleterious for those co-residing with the children. Further, life-long stress and burden may lead to poor physical health and memory functioning and more depressive symptoms in old age. Yet, stress and burden may affect parents of children with severe, long-term mental illness more profoundly leading to poorer functioning than parents of children with disabilities in old age. The purpose of the present study was to expand on the previous study by evaluating whether interpersonal and intrapersonal resources act as buffers of stress in parents of children with disabilities or long-term mental illnesses in old age. Including a second group of parents allowed for between group comparisons to determine if parenting a child with severe, long-term mental illness leads to worse functioning across multiple domains than parents of children with disabilities in old age. Further, the current study used two measures caregiver burden to assess variations the in experiences of stress for these parents. An additional focus of the current study was to examine multiple domains of functioning that are highly relevant in old age (i.e., physical and cognitive) to determine if the deleterious effects of raising a child with special needs exists across multiple domains.

As such, the hypotheses of the current study are:

Hypothesis 1. Parents of children with severe, long-term mental illnesses would be worse off across all domains in old age. Specifically, parents of children with severe, long-term mental illnesses would have greater levels of caregiver burden, as well as lower rates of self-reported health and memory, and higher rates of depressive symptoms, than parents of children with intellectual and developmental disabilities, consistent with previous research in earlier years (Magaña et al., 2004; Ghosh et al., 2012; Seltzer et al., 2004). Parents of children with severe,

long-term mental illness would also have lower levels of social participation and psychological well-being than parents of children with disabilities.

Hypothesis 2. Parents co-residing with their adult offspring with intellectual and developmental disabilities and severe mental illness would be worse off than non-co-resident parents across all domains in old age. Specifically, co-resident parents would have greater levels of caregiver burden, lower rates of self-reported health and memory, higher rates of depressive symptoms, and lower levels of social participation and psychological well-being than non-co-resident parents of adult offspring with disabilities and long-term illnesses.

Hypothesis 3. Higher levels of objective and subjective caregiver burden would be associated with poorer physiological, cognitive, and psychological functioning.

Hypothesis 4. In old age (early 70s), higher levels of interpersonal (social participation) and intrapersonal (psychological well-being) resources would be positively related to physiological, cognitive, and psychological functioning.

Hypothesis 5. Interpersonal (social participation) and intrapersonal (psychological well-being) resources would serve as moderators of the effects of subjective and objective caregiver burden on physiological, cognitive, and psychological functioning. Specifically, caregiver burden would be a relatively stronger predictor for parents with low social participation and psychological well-being than those with high levels.

## Methods

### Participants (WLS):

The study used data from the Wisconsin Longitudinal Study (WLS). The WLS is a publicly available data set that consists of information obtained from a random sample of 10,317 men and women who graduated from Wisconsin high schools in 1957 when they were approximately 17-18 years old (Hauser, Sheridan, & Warren, 1999). The participants were subsequently contacted to obtain follow up information in 1975 when they were in their mid-30's. Two years later, in 1977 the study was expanded to include a sub-sample of 2000 siblings of the primary graduate respondents. Further follow-ups of the graduates and their siblings were conducted in 1992-93 when they were in their early to mid-50's, which is referred to as the



midlife data collection wave, 2004-2006 when they were in their mid-60's, referred to as the early old age wave, and 2011 when they were in their early 70s, referred to as the old age wave. Subsequent waves included the graduates and a randomly selected sibling of all respondents with at least one brother or sister. In all, 5,823 siblings participated in one or more of these data-collection points in addition to the original respondents and siblings. For the present study, data was drawn from the 2011 (old age) data collection wave. Respondents were contacted over the phone in each of the time waves for phone interviews. After completion of the phone interview the respondents were sent a self-administered mail-back questionnaire packet with various measures to complete and return by mail. The 2011 waves include all variables relevant to this study, including social participation, depression, burden, well-being, co-residence, physical health, cognitive functioning, and health related quality of life data.

#### Participants (Groups):

Two groups of participants, parents of children with developmental disabilities and parents of children with severe, long-term mental illness, were selected for the current investigation. The group of parents of children with developmental disabilities and severe, long-term mental illness, is similar to samples identified and used in previous analyses (Ghosh, Greenberg, & Seltzer, 2012; Seltzer et al., 2011). Specifically, parents in the WLS who had a child with developmental disabilities or severe, long-term mental illness were identified in the 2004–2006 survey. During this wave a “child screener” was administered over the phone, and consisted of a series of questions (maximum of 31) which began by asking parents if they had any children (living or deceased). If yes, the parent was asked if any of those children had a developmental disability or severe mental illness as well as the specific diagnosis. For inclusion in the developmental disability group, the parent needed to have indicated that the identified child had a specific intellectual and developmental disability, or in describing the child the parent needed to use terms such as developmental disability, mental retardation, or cognitive disability. If a parent endorsed not knowing the specific diagnosis, yet also reported that the child had experienced difficulties in school, follow-up questions were asked about issues such as whether the child has below-average intelligence or participated in special education classes. If so, the participant was included in the intellectual and developmental disabilities group, consistent with previous research conducted with the sample (Seltzer et. al., 2011). For inclusion in the severe

mental illness group, parents needed to have indicated that the identified child had been previously diagnosed by a health professional with a severe mental illness including schizophrenia or bipolar disorder. Major clinical depression was also included in the severe mental illness group if the disorder was severe enough to require hospitalization or limited the person's ability to carry on activities of daily living. If so, they were included in the severe mental illness group consistent with previous research using the sample (Ghosh et al., 2012).

To be included in the present study, parents needed to have at least one of the caregiver burden questions (i.e., subjective burden, direct care) answered, as well as at least one in-person (health related quality of life, memory) and at least one mail (depressive symptoms, social participation, psychological well-being) questionnaire answered. With this inclusion criteria, all included participants had data for at least five of the nine variables used in the current study. In addition, parent respondents could not have reported having a deceased child due to the known effects that bereavement has on parent's well-being throughout the life course (Rogers et al., 2008; Floyd et al., 2013). These inclusion criteria produced a total sample of 418 parents including 172 men (41.1%) and 246 women (58.9%). The parents that comprise the intellectual and developmental disabilities parenting group consist of 150 respondents including 76 men (50.7%) and 74 women (50.3%). The 268 parents that comprise the severe mental illness parenting group consist of 96 men (35.8%) and 172 women (64.2%). The identified disabilities of the offspring in the intellectual and developmental disabilities group consist of 46 with intellectual disability, 20 with Down syndrome, 23 with cerebral palsy, 22 with an autism spectrum disorder, 8 with traumatic brain injury, 17 with specific intellectual and developmental disability diagnoses or conditions, 14 with other non-specific intellectual and developmental disability conditions including low IQ. The identified mental illnesses of the offspring in the severe mental illness parenting group consist of 207 with bi-polar, 56 with schizophrenia, and 5 with major depression resulting in hospitalization.

Table 1 includes means and standard deviations for the demographic information for the intellectual and developmental disabilities and severe mental illness parenting groups. Results indicate that the groups did not differ on any of the 1957 socio-demographic background variables or 2011 except for current marital status with the IDD parenting group having significantly higher rates of being in a current marriage than the SMI parenting group.

## Measures

**Subjective burden.** Consistent with other research using the same samples of participants (Piazza et al., 2014) a standardized measure of subjective caregiver burden was used—the Zarit Burden Scale (Zarit et al., 1980). This scale consists of 30 items (27 negative items and 3 positive items) assessing the personal strains of caregiving based on a 3-point scale with 1 meaning “not at all”, 2 meaning “somewhat”, and 3 meaning “extremely.” Some examples of various items include: “I feel that my son/daughter is dependent,” “I feel uncomfortable when I have friends over because of my child,” and “I feel that I don’t have enough money to support my child in addition to the rest of our expenses.” To score the measure, ratings for the 3 positive items were summed and subtracted from the sum of the ratings for the 27 negative items. Therefore, total burden scores will range from 18 (lowest degree of burden) to 78 (highest degree of burden) consistent with previous studies using this measure (e.g., Piazza et al., 2014). The Zarit Burden Scale has also demonstrated adequate psychometric properties. It demonstrated good reliability in a sample of mothers of children with disabilities, yielding alphas between .82 and .84 (Kim et al., 2003). The scores also demonstrated good construct validity in a study of family caregivers in which lower burden scores were found to be related to a greater sense of personal efficacy (Zeiss, Gallagher-Thompson, Lovett, Rose, & McKibbin, 1999).

**Direct care.** The direct care variable is a dichotomous variable consisting of whether or not the parent provided any direct care to their adult offspring. The question about caregiving comes from a “non-normative extension interview,” which is an additional interview module given to respondents identified as having a child with a developmental disability or long-term, serious mental illness. The interview asked many questions about the child’s condition and the respondent’s experience caring for the child. The question used in the current study asked, “Not including social or entertainment activities or watching TV, how many hours in a typical week do you help your [selected non-normative] child in care related activities, such as getting dressed, grooming, shopping, transportation, chores or other activities?” The respondent then answered with the total number of hours. Number of hours per week caring has successfully discriminated between rates of coronary heart disease in female caregivers of disabled or ill spouses or parents in old age, with high number of hours per week (i.e., 9 or more) being associated with elevated risk for heart disease (Lee, Colditz, Berkman, & Kawachi, 2003). When

analyzed, a small percentage (16%) of the participants in the SMI parenting group reported spending any time directly caring for their adult offspring, leading to variable that was not evenly distributed and was associated with only one of the parenting groups. As such, a binary variable of providing any amount of care and not providing any direct care at all was created. In the IDD parenting group 73 (48.7%) reported providing direct care to their child and 77 (51.3%) not providing direct care. In the SMI parenting group, 43 (16%) reported providing direct care and 225 (84%) reported providing no direct care.

Co-residence status. The group of parents of individuals with developmental disabilities and severe mental illness will be further divided into two groups, those whose son or daughter were currently living with the parent respondent and those whose son or daughter lived away from the respondent's home. Olsen et al. (2018) found that when parents were in their early 60s, 37.2% of children with intellectual and developmental disabilities were still co-residing with the parents. Further, Seltzer et al. (2011) found that 51% of the adult children with intellectual and developmental disabilities lived at home when the parents were in their early 50s, and 39% lived at home when their parents were in their early 60s. In a separate study, Greenberg et al. (2004) found that 90% of children with Down syndrome, 45% of children with schizophrenia, and 33% of children with autism were co-residing with their parents when the parents were age 55 or older. Eight total participants did not report co-residence data. Those participants were included in the study but are not accounted for in the analyses examining co-residence status. In the intellectual and developmental disabilities group, 47 (32.6%) were co-residing and 97 (67.4%) were not co-residing in their adult offspring. In the severe mental illness group 29 (10.9%) were co-residing and 237 (89.1%) were not co-residing in their adult offspring.

Social participation. Social participation was assessed using three separate indices. One index included the level of involvement in organizations in which the respondent was a member (endorsed from a list of 17 organizations such as charity or welfare organizations, civic groups, labor unions, neighborhood organizations, sports teams, 1 = very little, 2 = some, 3 = quite a bit, 4 = a great deal). The total number of organizations endorsed has been used as an index of social participation in other research using this sample (Mailick Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001). Another index of social participation was a measure of friendship participation asked as, "How many times in the past four weeks have you gotten together with friends? We

mean like going out together or visiting in each other's homes.” Similarly, family participation will also be used with the question, “How many times, if at all, during the past four weeks have you gotten together socially with relatives?” Of note, the family participation variable does not explicitly state whether or not the relatives with whom they are getting together socially live in the same household as the respondent. With both questions, the participant responded by giving the appropriate number of times. Each index has been shown to be associated with indices of psychological functioning (i.e., depressive symptoms) in aging parents of children with intellectual and developmental disabilities independently (Olsen et al., 2018) and as composites (Seltzer et al., 2011).

**Psychological well-being.** A modified version of Ryff’s Scales of Psychological Well-Being (Ryff, 1989; Ryff & Keyes 1995) was used. The measure covers six dimensions of well-being including: Self-Acceptance, Positive Relations with Others, Autonomy, Environmental Mastery, Purpose in Life, and Personal Growth. Ryff and Keyes (1995) found that a six factor structure is the best fit to the data. The WLS respondents received reduced versions of all six subscales of the Ryff’s Scales of Psychological Well-Being. All items are rated on a scale of 1 to 6 (1 meaning agree strongly to 6 meaning disagree strongly). The items were reverse coded so that a higher score reflect higher levels of well-being consistent with previous studies using the measure (Seltzer et al., 2011). Each subscale has five or six questions for a possible total score between 1 (lowest possible) and either 30 (self-acceptance, personal growth, environmental mastery, autonomy) or 36 (purpose in life, positive relations). A well-being composite was computed by summing the standardized subscale scores of the six dimensions of the measures, thus an overall well-being score was used consistent with previous research (Seltzer et al., 2011). The internal consistency coefficients of Ryff’s original validation of the full scales were quite high (between 0.86 and 0.93). In the same study, the test–retest reliability coefficients were also high (0.81–0.88) over a six-week period for a subsample of the participants (Ryff, 1989).

**Health related quality of life (HRQoL).** HRQoL was measured by the Health Utilities Index (HUI-3). The HUI-3 is a self-report measure of overall health status that includes vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain (Horsman, Furlong, Feeny, & Torrance, 2003). All of the attributes are assessed by five or six levels of health status or functionality. For example, the level 1 evaluation of vision is: “able to see well enough to read

ordinary newsprint and recognize a friend on the other side of the street” whereas the level 6 evaluation is: “unable to see at all.” The level 1 evaluation of Emotion is: “happy and interested in life” and the level 5 evaluation is: “so unhappy that life is not worthwhile.” Consistent with previous research using the HUI-3 (e.g., Song et al., 2010), the measure will be scored using a standardized scoring algorithm. The algorithm gives a multi-attribute summary HUI-3 score ranging from 0 to 1, where “0” means poorest health status and “1” means perfect health. The HUI-3 has been found to be an important measure for distinguishing bereaved parents of children who have died (Song et al., 2010). Other studies have found that HUI-3 scores have good test-retest reliability and predictive and construct validity (Feeny et al., 2002; Feeny, Huguet, McFarland, & Kaplan, 2009; Maddigan, Feeny, Majumdar, Farris, & Johnson, 2006). In the study, nine participants (2.2%) had a score below zero, which is indicative of a theoretical state worse than death.

**Memory functioning.** Memory was measured by the Immediate and Delayed Word Recall created for the Wisconsin Longitudinal Study. During the old age data collection wave, 80% of participants were randomly selected to take part in the cognitive modules. The selected 80% were individually read a list of ten common words and asked to recall as many words as possible from the list. As a distractor, the participants were then read a short series of questions for approximately 10 minutes. After the 10-minute delay, the interviewer again asked the participant to recall as many words from the original list as possible. Scores for immediate and delayed recall are the sum of the number of words correctly recalled under each condition. A congruent measure (i.e., same measure with different words) has been shown to successfully discriminate levels of declarative memory in stressed and unstressed participants (Elzinga, Bakker, & Bremner, 2005).

**Depressive symptoms.** Depressive symptoms were measured by the Center for Epidemiological Studies—Depression Scale (CES-D; Radloff, 1977), which has been used successfully in samples on midlife and later life parenting of adult children with disabilities and severe long-term illnesses (Floyd et al., 2013; Barker, Hartley, Seltzer, Floyd, Greenberg, & Orsmond, 2011; Taylor, Greenberg, Seltzer, & Floyd, 2008; Rogers et al., 2008). For each of 20 depressive symptoms, the respondent was asked to indicate how many days in the past week the symptom was experienced. The data were recoded into four categories (0 = never, 1 = 1–2 days,

2 = 3–4 days, and 3 = 5–7 days), consistent with the conventional scoring of the CES-D. The total score was the sum of the ratings for the 20 items. Scores could range from 0 to 60 with higher scores indicating more depressive symptoms, and a score of 16 or greater indicating the risk of clinical depression. The CES-D has also been found to have adequate internal consistency ( $\alpha = .86$ ) in the sample of parents of children with intellectual and developmental disabilities (Olsen et al., 2018).

### Analyses

**Imputation of Missing Values.** To retain sample sizes, multiple imputation (MI) was used to estimate missing data for participants with partial data. Multiple imputation is a preferred technique for handling missing data and has numerous advantages over other approaches (Azur, Stuart, Frangakis, & Leaf, 2011). The missing at random (MAR) assumption was tested using the Missing Value Analysis (MVA) procedure. This analysis describes the pattern of missing data to determine if imputation of the variables is permissible based on whether or not the values are missing randomly. The results of the MVA indicated that 8.14% of the data was missing, including 90 (21.5%) immediate and delayed recall, 50 (12.0%) Zarit Burden Interview, 35 (8.4%) Health Utility Index 3, 49 (11.7%) family, 47 (11.2%) friend, 27 (6.5%) organization, 21 (5.0%) depressive symptoms, and 7 (1.7%) psychological well-being data. No other variables in the study had any missing data with the exception of co-residence, which was not estimated. Also, Little's missing completely at random test was not significant  $\chi^2(14427, N = 418) = 14553.74, p = 0.23$ . In addition, the memory scores were intentionally sampled randomly at 20% missing data, indicating that the mechanism of missingness was completely random for that variable. Consistent with the guidelines by Cheema (2014), the multivariate imputation regression method was employed to generate eight datasets with complete information for individuals with missing data. The mean of the estimated values was used in the analyses to provide the most reasonable imputation.

### Hypotheses

Hypothesis 1. Independent sample t-tests and chi-squared were conducted to test the hypothesis that parents of adult offspring with severe, long-term mental illnesses would have significantly worse scores on levels of caregiver burden, social participation, psychological well-

being, and physiological health, memory, and psychological functioning than parents of adult offspring with intellectual and developmental disabilities.

Hypothesis 2. Similar to hypothesis 1, independent samples t-tests and chi-squared were conducted to test the hypothesis that parents co-residing with their adult offspring with disabilities or long-term illnesses would have significantly worse scores on all of the variables in the study than those parents not co-residing with their adult offspring.

Hypothesis 3. Hypotheses 3, 4, and 5 were simultaneously tested in a single linear regression. The first step of the linear regression analysis was used to test the hypothesis that higher levels of caregiver burden would be associated with greater cognitive, psychological, and physiological health difficulties. Each continuous dependent variable (physiological health, memory, and psychological functioning) was regressed on the continuous predictor variable (caregiver burden) entered in step one of the regression analysis. Sex, parenting group, and marital status were also entered in step one. Sex was entered in order to account for the known pattern of sex differences in many of the predictor and outcome variables. Parenting group was entered to account for potential group differences that were examined in subsequent analyses. Marital status was entered to control for the group difference on this variable.

Hypothesis 4. To test the hypothesis that higher levels of interpersonal (social participation) and intrapersonal (psychological well-being) resources would be positively related to physiological health, memory, and psychological functioning outcomes, organization, friend, and family participation (social participation variables) and psychological well-being were entered at step two of the regression. The main effects of the social participation variables and psychological well-being were examined independently and after the main effects in the previous hypothesis.

The previous analyses raised the question of whether social participation and psychological well-being would moderate the effects of caregiver burden on the outcome measures for only one of the disability groups. To answer this question, the analyses conducted with the entire sample were conducted individually by each disability group. Similar to previous analyses, the cross products of the Caregiver Burden X Resources were entered stepwise and evaluated for significance when entered separately after the main effects, with one set of analyses for each parenting group. Three-way interactions with cross products of the X Caregiver



Burden X Resources X Disability Group were included to determine if any of the two-way interactions were only significant within one of the disability groups.

Hypothesis 5. To test the hypothesis that interpersonal and intrapersonal resources (social participation and psychological well-being) would serve as moderators of the effects of caregiver burden on physiological health, memory, and psychological functioning, two-way interactions were entered into the regression analysis at step 3 (Cohen & Cohen, 1975). Specifically, the cross products of the Caregiver Burden X Resources were entered stepwise and evaluated for significance when entered separately after the main effects. Significant beta weights for the product terms were examined as indicators for an interaction effect. Interaction terms were calculated after mean-centering all continuous predictor variables in order to reduce the multicollinearity between the main effects and the interaction terms (Holmbeck, 2002). All two-way interactions, regardless of significance are reported in the tables.

Follow-up Analyses by Co-residence and Sex. As follow up analyses to examine if any main effects or two-way interactions between burden and resources are only significant in the co-resident parenting group, separate analyses were conducted with co-resident status entered in step one along with caregiver burden variables, with the hypothesis that two-way interactions may only exist in the co-resident parenting group. Three-way interactions with cross products of the Co-Resident Status X Caregiver Burden X Resources were included to determine if any of the two-way interactions were only significant within the co-resident group.

The final set of follow up analyses examined if any of the two-way interactions were only significant for men or women in each of the two parenting groups. Specifically, analyses were conducted only with the women in the severe mental illness parenting group, only with the women in the developmental disabilities parenting group, only with the men in the severe mental illness parenting group, and only with the men in the developmental disabilities parenting group to determine if the interactions are only relevant to mothers or fathers under the different parenting circumstances. Separate analyses for each sex were conducted instead of testing three-way interactions involving gender in order to reduce the number of predictor variables in analyses with small n sizes.

Sample Characteristics. Demographic and background variables were analyzed by a general linear model analysis to determine if the two groups differed in personal and family

background characteristics. Background characteristics of the participants were assessed during their junior year of high school in 1957, and later life socio-demographic variables were assessed in 2011 (early 70s). Table 1 shows means and standard deviations of the family background characteristics and socio-demographic variables by parenting group. The intellectual and developmental disabilities and severe mental illness groups were comparable with respect to all 1957 family background variables, including age, high school IQ score, family income, father's education, and community size. The two groups were also comparable with respect to all except one of the 2004 socio-demographic variables, including number of children born, total personal income, total household income, and years of education. A chi-square test of independence examining differences in later life marital status was significant,  $\chi^2(1, N = 418) = 9.03, p < 0.01$ , indicating that the IDD parenting group had higher rates of being in a current marriage (77.3%) than the SMI parenting group (63.1%). As such, marital status was entered into the analyses as a dummy-coded variable to control for the potentially confounding variable.

Table 1

*Demographic Variables for Intellectual and Developmental Disabilities Parenting Group and Severe Mental Illness Parenting Group*

Variable	IDD Group	SMI Group	$t/\chi^2$	$df$
Age	71.86 (4.62)	71.50 (3.92)	-0.81	416
IQ score	102.62 (15.77)	105.58 (15.29)	-1.83	395
Family income in 1957 in dollars	9,013 (4,756)	10,341 (9,591)	-1.29	276
Community Population Size in Thousands 1957	130.63 (180.15)	112.12 (167.51)	1.05	416
Father Occupational Status Score 1957	33.44 (22.67)	34.16 (23.06)	0.73	411
Number of Children Ever Born	3.29 (2.58)	3.26 (2.23)	0.09	416
Respondent Total Personal Income in Dollars 2011 (rounded)	27,477 (27,823)	36,313 (102,358)	-1.04	416
Respondent Total Household Income in Dollars 2011 (rounded)	46,127 (40,782)	57,318 (195,505)	-0.69	416
Marital Status in 2011 <sup>a</sup>				
Currently married	116 (77.3%)	169 (63.1%)	9.44	p < 0.01
Not currently married	34 (22.7%)	99 (36.9%)		

a indicates chi-squared

Table 2 Bivariate Correlations (n=418)

	HRQoL	Memory	Depressive Symptoms	Caregiver Burden	Direct Care	Org	Friend	Family	PWB	Sex	Marital Status	Group
HRQoL	1											
Memory	0.19**	1										
Depression	-0.49**	-0.17**	1									
Burden	-0.19**	-0.01	0.22**	1								
Direct	-0.03	-0.01	0.05	0.12*	1							
Org	0.09	0.07	-0.07	0.05	0.07	1						
Friend	0.07	-0.04	0.10*	0.05	-0.10*	0.24**	1					
Family	0.01	-0.06	0.07	0.06	0.01	0.02	0.33**	1				
PWB	0.36**	0.19**	-0.52**	-0.10*	-0.02	0.24**	0.22**	0.08	1			
Sex	0.02	-0.22**	-0.08	-0.04	0.03	-0.01	-0.05	-0.06	-0.06	1		
Marital Stat	0.10*	-0.04	-0.16**	-0.03	0.04	0.07	-0.03	-0.03	0.07	0.28**	1	
Group	-0.04	0.10*	0.06	-0.01	-0.37**	-0.04	0.05	-0.03	0.03	-0.15**	-0.15**	1

HRQoL indicates Health Related Quality of Life

Depression indicates Depressive symptoms

Burden indicates Caregiver Burden

Direct indicates Direct Care

Org, Friend, Family indicate Social Participation variables

PWB indicates Psychological Well-Being

## Results

In order to control for the possibility that previous mental illness among parents might account for poorer health and mental health outcomes in old age, all of the analyses included previous mental illness entered as a main effect and in interaction with other predictors. The predictive effects of other variables generally were not affected by this control variable, with the exception of one significant interaction which is reported below. Table 2 presents the bivariate correlations of all variables used in the study.

Independent samples t-tests and chi-squared tests contrasted the mothers and fathers in the groups. These results are given in Table 3. Of the nine tests conducted, only one demonstrated significant differences between sexes. Mothers obtained significantly higher cognitive scores than fathers.

### Parenting group differences

The results for hypothesis 1 are given in Table 4. The hypothesis proposed that the parents in the severe mental illness parenting group as opposed to the intellectual and developmental disabilities group would have significantly worse functioning in all domains, including greater burden, fewer resources, and poorer functioning. Of the nine tests conducted, only two demonstrated significant group differences, and these differences were in the opposite direction than expected. Specifically, chi-squared analysis showed that a significantly higher percentage of parents of adult offspring with IDD spent time providing direct care for their child than parents of children with SMI. In addition, the parents of adult offspring with developmental disabilities and parents of adult offspring with severe mental illness significantly differed on memory functioning, with the SMI parenting group having significantly higher scores than the IDD parenting group. Thus, the hypothesis that parents of offspring with mental illness would demonstrate greater burden, fewer resources, and poorer functioning across domains was not supported.

### Co-resident status group differences

The results for hypothesis 2, are given in Table 5. The hypothesis proposed that co-resident parents as opposed to non-co-resident parents would have significantly worse functioning in all domains, including greater burden, fewer resources, poorer functioning, and

more time spent caring for their adult offspring. Of the nine tests conducted, only two demonstrated significant group differences, with both being in the expected direction. Consistent with the hypothesis, chi-squared analysis showed that a significantly higher percentage of co-resident parents spent time providing direct care for their child than non-co-resident parents. Also consistent with the hypothesis, co-resident parents reported significantly lower rates of friend participation than non-co-resident parents. Thus, the hypothesis was only supported for two of the variables.

Table 3

*Mean Difference between Mothers (n=246) and Fathers (n=172)*

Variable	Mothers	Fathers	<i>t</i>
Subjective Burden	13.55 (8.13)	12.94 (8.39)	0.75
HRQoL	0.71 (0.28)	0.73 (0.27)	-0.41
Memory	9.54 (3.18)	8.19 (2.67)	4.55***
Depressive Symptoms	10.04 (8.18)	8.44 (8.44)	1.59
Organization Participation	26.13 (6.30)	26.00 (5.93)	0.24
Friend Participation	3.68 (3.71)	3.32 (3.14)	1.05
Family Participation	3.20 (2.74)	2.90 (2.46)	1.14
Psychological Well Being	151.23 (21.28)	148.78 (19.65)	1.19
Direct care <sup>a</sup>			
No caring	178 (72.4%)	120 (69.8%)	0.57
At least one hour of caring	68 (27.6%)	52 (30.2%)	

a indicates chi-squared

Table 4

*Mean Difference Between IDD (n=150) and SMI Parents (n=268)*

Variable	IDD	SMI	<i>t</i>
Subjective Burden	13.37 (7.38)	13.26 (8.69)	0.12
HRQoL	0.73 (0.26)	0.71 (0.28)	0.71
Memory	8.57 (3.01)	9.22 (3.06)	-2.08*
Depressive Symptoms	8.88 (7.08)	9.85 (8.91)	-1.15
Organization Participation	26.43 (6.08)	25.87 (6.18)	0.89
Friend Participation	3.31 (3.00)	3.66 (3.73)	-1.00
Family Participation	3.19 (2.76)	3.01 (2.55)	0.68
Psychological Well Being	149.51 (20.54)	150.62 (20.72)	0.52
Direct care <sup>a</sup>			
No caring	73 (48.7%)	225 (84.0%)	59.04***
At least one hours of caring	77 (51.3%)	43 (16.0%)	

a indicates chi-squared

Table 5

*Mean Difference Between Co-Resident (n=76) and Non-Co-Resident Parents (n=334)*

Variable	Co-Resident	Non-Co-Resident	<i>t</i>
Subjective Burden	14.12 (8.02)	13.19 (8.32)	0.89
HRQoL	0.70 (0.31)	0.72 (0.26)	-0.69
Memory	9.37 (2.97)	8.93 (3.03)	1.13
Depressive Symptoms	9.96 (8.15)	9.39 (8.35)	0.54
Organization Participation	26.16 (5.52)	26.11 (6.31)	0.06
Friend Participation	2.75 (2.95)	3.70 (3.57)	-2.15*
Family Participation	3.28 (2.74)	3.02 (2.60)	0.77
Psychological Well Being	148.26 (21.97)	150.71 (20.09)	-0.94
Direct care <sup>a</sup>			
No caring	30 (39.5%)	265 (79.3%)	48.90***
At least one hours of caring	46 (60.5%)	69 (20.7%)	

a indicates chi-squared

### Sex differences related to parent group and co-resident status

To evaluate whether there were interactions among grouping variables that could not be detected with the independent samples t-tests, three-way ANOVAs contrasting the different parenting groups, resident groups, and mothers and fathers were conducted. Tables 6 and 7 present the results of ANOVAs including two-way and three-way interactions. ANOVA analysis was not conducted for direct care given that the variable is dichotomous. Of the eight analyses conducted family participation demonstrated a significant two-way interaction, and a significant three-way interaction. Table 6 shows the ANOVA results for family participation. For the significant two-way Group X Sex interaction, within the IDD group, mothers ( $M = 3.51$   $SD = 2.94$ ) had significantly more family participation than the fathers ( $M = 2.88$   $SD = 2.54$ ). In the SMI group the finding was reversed as the fathers ( $M = 3.72$   $SD = 2.82$ ) had significantly more family participation than the mothers ( $M = 2.83$   $SD = 2.54$ ). For the significant three-way Group X Co-residence X Sex interaction, mothers had more family participation in all situations except one. Specifically, within the IDD group, co-resident mothers ( $M = 3.75$   $SD = 2.84$ ) had higher family participation than co-resident fathers ( $M = 2.78$   $SD = 2.29$ ) and non-co-resident mothers ( $M = 3.31$   $SD = 2.44$ ) had more family participation than non-co-resident fathers ( $M = 2.89$   $SD = 2.63$ ). Further, non-co-resident mothers in the SMI group also had higher rates of family participation ( $M = 3.14$   $SD = 2.42$ ) than non-co-resident fathers in the SMI group ( $M = 2.73$   $SD = 2.84$ ). Conversely, co-resident fathers in the SMI group had the highest rates of family participation of all groups ( $M = 4.72$   $SD = 3.32$ ) with co-resident mothers in the SMI group having the lowest family participation of all groups ( $M = 2.53$   $SD = 2.41$ ). Table 7 shows the ANOVA results for cognitive functioning. There was a main effect of sex, with mothers having significantly higher rates of memory functioning than fathers. There were no two-way or three-way interactions in cognitive functioning.



Table 6

*Three Way ANOVA with Group, Co-Residence and Sex Predicting Family Participation*  
(*N=418*)

Source	Sum of Squares	df	F
Group	0.45	1	0.07
Co-Residence	9.66	1	1.41
Sex	0.46	1	0.07
GroupXCo-Residence	3.51	1	0.51
GroupXSex	33.53	1	4.89*
Co-ResidenceXSex	14.01	1	2.04
GroupXCo-ResidenceXSex	32.78	1	4.78*

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

Table 7

*Three Way ANOVA with Group, Co-Residence and Sex Predicting Cognitive Functioning*  
(*N=418*)

Source	Sum of Squares	df	F
Group	29.82	1	3.44
Co-Residence	25.47	1	2.94
Sex	67.68	1	7.82**
GroupXCo-Residence	2.84	1	0.33
GroupXSex	2.63	1	0.30
Co-ResidenceXSex	9.97	1	1.15
GroupXCo-ResidenceXSex	11.70	1	1.35

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

### Caregiver burden as a predictor of functioning in old age

In order to test the hypothesis that caring for an adult offspring would lead to worse functioning in old age for parents, regressions were conducted to examine if higher levels of caregiver burden were associated with poorer physiological, cognitive, and psychological functioning. Tables 8-10 present the results of the regressions evaluating the main effects of subjective burden and direct care on health related quality of life, memory, and depressive symptoms. The control variables and burden variables were entered at step 1. They accounted for significant variance, as shown by the R squared values in Tables 6-8, in health related quality of life  $F(5, 412) = 3.96, p < .01.$ , memory  $F(5, 412) = 4.70, p < .001.$ , and depressive symptoms scores,  $F(5, 412) = 6.61, p < .001.$  Regarding the control variables, marital status significantly predicted depressive symptoms, with persons not currently married ( $M = 11.41, SD = 9.00$ ) reporting more depressive symptoms than those currently married ( $M = 8.62, SD = 7.81$ ). Concerning the burden variables, subjective burden significantly predicted health related quality of life ( $p < .001$ ) and depressive symptoms ( $p < .001$ ). The directions of these effects were consistent with the hypothesis, with higher levels of subjective burden associated with lower levels of health related quality of life and high levels of depressive symptoms for the parents. Subjective burden scores did not significantly predict memory scores ( $p = 0.74$ ). Also, direct care did not significantly predict any functioning outcomes; i.e., health related quality of life ( $p = 0.74$ ), memory ( $p = 0.60$ ), or depressive symptoms ( $p = 0.29$ ). Thus, the hypotheses that caregiver burden would be negatively associated with functioning was partially supported, and only for the measure of subjective burden.

Additional follow up analyses, using the same structure as above, were conducted individually by mothers and fathers. Rather than testing interactions of sex with other predictors, separate analyses were conducted to ensure the effects remained adequately powered. Appendices 1-5 show that each of the main effects that were significant for the entire sample was significant in each gender group individually. That is the significant effects found above were repeated in analyses with the separate groups of women and men.

### Interpersonal and intrapersonal resources as predictors of functioning in old age

The hypothesis that interpersonal and intrapersonal resources would be positively related to physiological, cognitive, and psychological functioning was evaluated by adding the three

resource variables at step 2 to the regressions predicting each of the three areas of functioning. Consistent with the hypothesis that greater social participation and psychological well-being would predict better functioning on the outcome variables, the addition of the social participation variables and psychological well-being at step 2 accounted for significant additional variance in health related quality of life,  $F_{\text{change}}(4, 408) = 14.02, p < .001$ , memory functioning,  $F_{\text{change}}(4, 408) = 4.76, p < .01$ , and depressive symptoms,  $F_{\text{change}}(4, 408) = 39.81, p < .001$ . The changes in R squared are given in Tables 8-10.

Regarding the social participation variables, as shown in Table 8-10, only one of the nine hypothesized main effects of the social participation variables was significant when entered at Step 2. Family participation, significantly predicted depressive symptoms ( $p = 0.04$ ) in the expected direction, with higher levels of family participation associated with lower levels of depressive symptoms. However, family participation did not significantly predict health related quality of life ( $p = 0.86$ ), or memory ( $p = 0.27$ ). Organization participation did not significantly predict either health related quality of life ( $p = 0.90$ ), memory ( $p = 0.37$ ), or depressive symptoms ( $p = 0.17$ ). In addition, friend participation did not significantly predict health related quality of life ( $p = 0.95$ ), memory ( $p = 0.10$ ) or depressive symptoms ( $p = 0.30$ ). Thus, the hypothesis that the social participation variables would have main effects on the outcomes was only detected in relation to family involvement as a predictor of relatively low levels of depressive symptoms. The main effects were also examined in the equations without the caregiver burden variables entered in step one in order to examine them without the potential shared variance between the two sets of predictor variables. Results were consistent, with only family participation significantly predicting depressive symptoms. Thus, the main effects in step one and step two are presented together in the tables.

In contrast to the results for the social participation variables, psychological well-being significantly predicted all three outcomes, including health related quality of life (see Table 8), memory functioning (see Table 9), and depressive symptoms (see Table 10), with higher levels of psychological well-being associated with higher levels of health related quality of life, better memory functioning, and lower depressive symptoms. Thus, the significant increases in R squared at step 2 are largely accounted for by the effects of psychological well-being and not by

the social participation variables. Thus, the hypothesis that psychological well-being would have a significant main effect on the outcome variables was supported.

As follow up analyses, the same analyses were conducted individually for the mothers and fathers. Results showed that each of the main effects that were significant for the entire sample was also significant for each gender individually, with two exceptions. Specifically, low levels of family participation predicting depressive symptoms, which was significant for the entire sample, was significant for fathers ( $p < .05$ ) but it was only a nonsignificant trend for the mothers ( $p = .09$ ) in the same direction. Friend participation, which was not significant for the entire sample, was a significant predictor of cognitive functioning for the mothers ( $p = .05$ ), but not for the fathers ( $p = .91$ ). As expected, higher levels of friend participation were associated with better memory functioning for the mothers.

Table 8

*Caregiver Burden Predicting Health Related Quality of Life Moderated by Social Participation and Psychological Well-Being (N=418)*

Variable	B	SE B	$\beta$	t	B	SE B	$\beta$	t
Step 1 Burden and Controls								
Caregiver Burden	-0.01	0.00	-0.19***	-3.87	-0.01	0.00	-0.15***	-3.32
Direct Care	-0.01	0.03	-0.02	-0.34	-0.01	0.03	-0.02	-0.33
Sex	-0.01	0.03	-0.02	-0.31	0.01	0.03	0.01	0.27
Group	-0.02	0.03	-0.03	-0.60	-0.02	0.03	-0.04	-0.81
Marital Status	0.05	0.03	0.09	1.77	0.03	0.03	0.06	1.20
R <sup>2</sup>			0.05**					
Step 2 Social and PWB								
Organizational					0.00	0.00	0.01	0.13
Friend					0.00	0.00	0.00	0.07
Family					0.00	0.01	-0.01	-0.18
Psychological Well Being					0.01	0.00	0.34***	7.11
$\Delta R^2$							0.12***	
Step 3 Interaction								
Burden X Organization					0.00	0.00	-0.02	-0.32
Burden X Friend					0.00	0.00	-0.01	-0.08
Burden X Family					0.00	0.00	0.06	1.09

Burden X PsyWellBeing	0.00	0.00	-0.03	-0.63
Direct Care X Organization	0.00	0.01	0.00	-0.02
Direct Care X Friend	0.03	0.01	0.16*	2.67
Direct Care X Family	-0.02	0.01	-0.10 <sup>a</sup>	-1.78
Direct Care X PsyWellBein	0.00	0.00	-0.01	-0.18
$\Delta R^2$				0.02***

---

\*p < .05. \*\*p < .01. \*\*\*p < .001.

a indicates a trend at p = 0.07

Table 9

*Caregiver Burden Predicting Cognition Moderated by Social Participation and Psychological Well-Being (N=418)*

Variable	B	SE B	$\beta$	t	B	SE B	$\beta$	t
Step 1 Burden and Controls								
Subjective Burden	-0.01	0.02	-0.02	-0.34	0.00	0.02	0.01	0.19
Direct Care	-0.19	0.35	0.03	0.53	0.11	0.35	0.01	0.31
Sex	-1.33	0.31	-0.22***	-4.27	-1.26	0.31	-0.20***	-4.12
Group	0.54	0.33	0.08	1.61	0.50	0.33	0.08	1.51
Marital Status	0.18	0.33	0.03	0.03	0.03	0.03	0.00	0.09
R <sup>2</sup>			0.04***					
Step 2 Social and PWB								
Organizational					0.02	0.03	0.05	0.13
Friend					-0.08	0.05	-0.09	0.07
Family					-0.06	0.06	-0.06	-0.18
Psychological Well Being					0.03	0.01	0.19***	3.70
$\Delta R^2$							0.04***	
Step 3 Interaction								
Burden X Organization					0.00	0.00	0.06	1.07
Burden X Friend					-0.01	0.01	-0.08	-1.38
Burden X Family					0.00	0.01	0.00	0.03

Burden X PsyWellBeing	0.00	0.00	-0.01	-0.13
Direct Care X Organization	0.01	0.06	0.02	0.23
Direct Care X Friend	0.12	0.11	0.07	1.09
Direct Care X Family	0.05	0.13	0.02	0.73
Direct Care X PsyWellBein	0.01	0.02	0.04	0.58
$\Delta R^2$			0.00	

---

\*p < .05. \*\*p < .01. \*\*\*p < .001.



Table 10

*Caregiver Burden Predicting Depressive Symptoms Moderated by Social Participation and Psychological Well-Being (N=418)*

Variable	B	SE B	$\beta$	t	B	SE B	$\beta$	t
Step 1 Burden and Controls								
Subjective Burden	0.21	0.05	-0.21***	4.31	-0.01	0.00	-0.15***	-3.32
Direct Care	-1.01	0.94	0.06	1.34	-0.01	0.03	-0.02	-0.33
Sex	-0.44	0.84	-0.03	-0.52	0.01	0.03	0.01	0.27
Group	0.94	0.90	0.05	1.05	-0.02	0.03	-0.04	-0.81
Marital Status	-2.43	0.89	-0.14**	-2.75	0.03	0.03	0.06	1.20
R <sup>2</sup>			0.07***					
Step 2 Social and PWB								
Organizational					0.08	0.06	0.06	1.37
Friend					-0.11	0.11	-0.05	-1.03
Family					0.36	0.14	0.11**	2.63
Psychological Well Being					-0.21	0.02	0.52***	-12.03
$\Delta R^2$							0.26***	
Step 3 Interaction								
Burden X Organization					-0.01	0.01	-0.05	1.02
Burden X Friend					0.00	0.01	-0.01	-0.18
Burden X Family					-0.03	0.02	0.09*	-1.92

Burden X PsyWellBeing	0.00	0.00	0.00	0.02
Direct Care X Organization	-0.01	0.13	0.00	-0.06
Direct Care X Friend	-0.23	0.26	-0.05	-0.89
Direct Care X Family	0.22	0.31	0.04	0.70
Direct Care X PsyWellBein	0.01	0.04	0.02	0.31
$\Delta R^2$				0.01***

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\*p < .05. \*\*p < .01. \*\*\*p < .001.

## Resources as moderators of caregiving burden

In order to test the hypothesis that social participation and psychological well-being would moderate the effects of caregiver burden on the outcome measures, two-way interactions between burden and each of the resources were tested at step 3. Tables 8-10 show that the addition of the Caregiver Burden X Interpersonal and Intrapersonal Resources interactions at step 3 did not overall account for significant additional variance in health related quality of life,  $F(8, 400) = 1.17$ ,  $p = 0.32$ , memory functioning,  $F(8, 400) = 0.76$ ,  $p = 0.64$ , or depressive symptoms,  $F(8, 400) = 0.97$ ,  $p = 0.46$ . Nevertheless, there were two specific predictions that were consistent with hypothesized moderation effects.

First, step 3 of Table 8 shows that there was a significant interaction between direct care and friend participation predicting health related quality of life. In order to evaluate the nature of the interaction, the effects of care vs. no care on HRQoL were examined at three levels of friend participation, 1 SD below the mean, the mean, and 1 SD above the mean. Figure 1 shows that, consistent with expectations, the negative impact of subjective burden on health related quality of life was smaller for parents experiencing high rates of friend participation than for those with lower rates of friend participation.

Second, step 3 of Table 10 shows that there was a significant interaction between subjective burden and family participation predicting depressive symptoms. In order to evaluate the nature of the interaction, the effects of subjective burden on depressive symptoms were examined at three levels of friend participation, 1 SD below the mean, the mean, and 1 SD above the mean. Figure 2 shows that, consistent with the hypothesis, the negative impact of subjective burden on depressive symptoms was smaller for parents experiencing high rates of family participation than for those with less family participation. There were no other significant interactions between interpersonal and intrapersonal resources and burden variables.

Figure 1

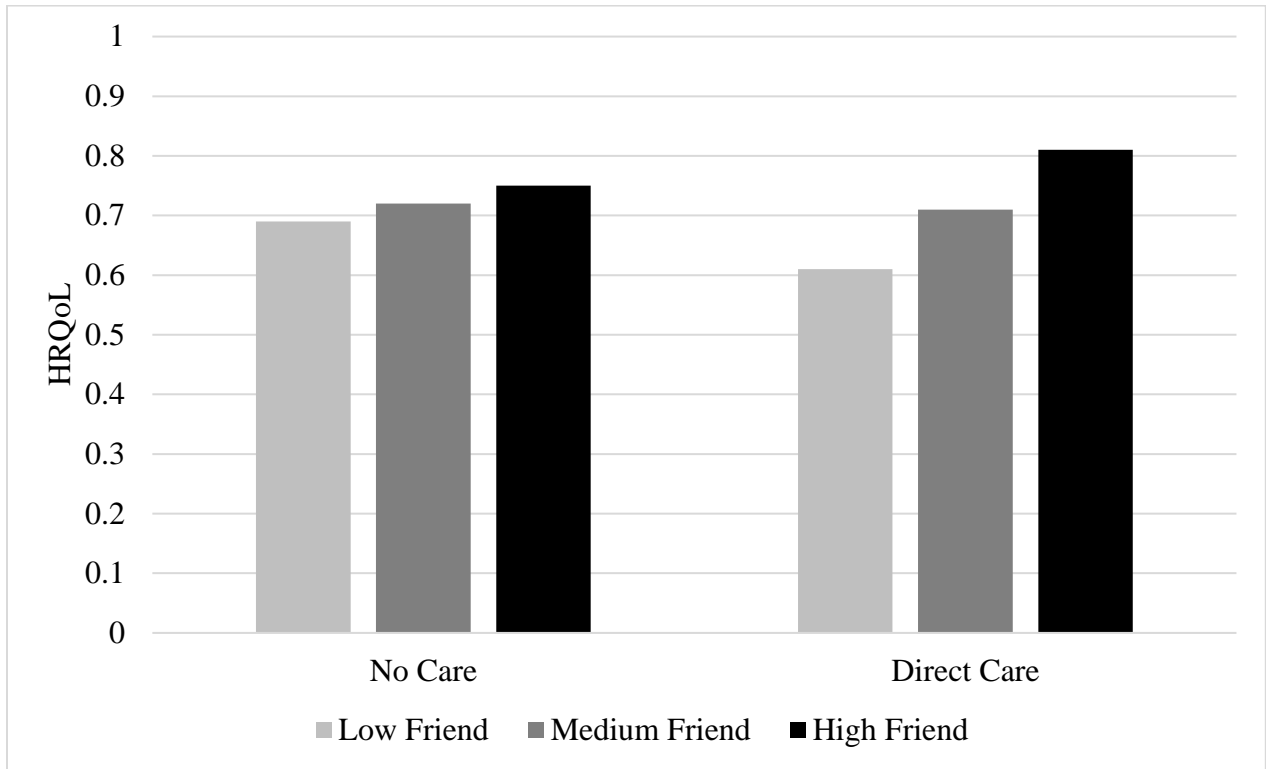
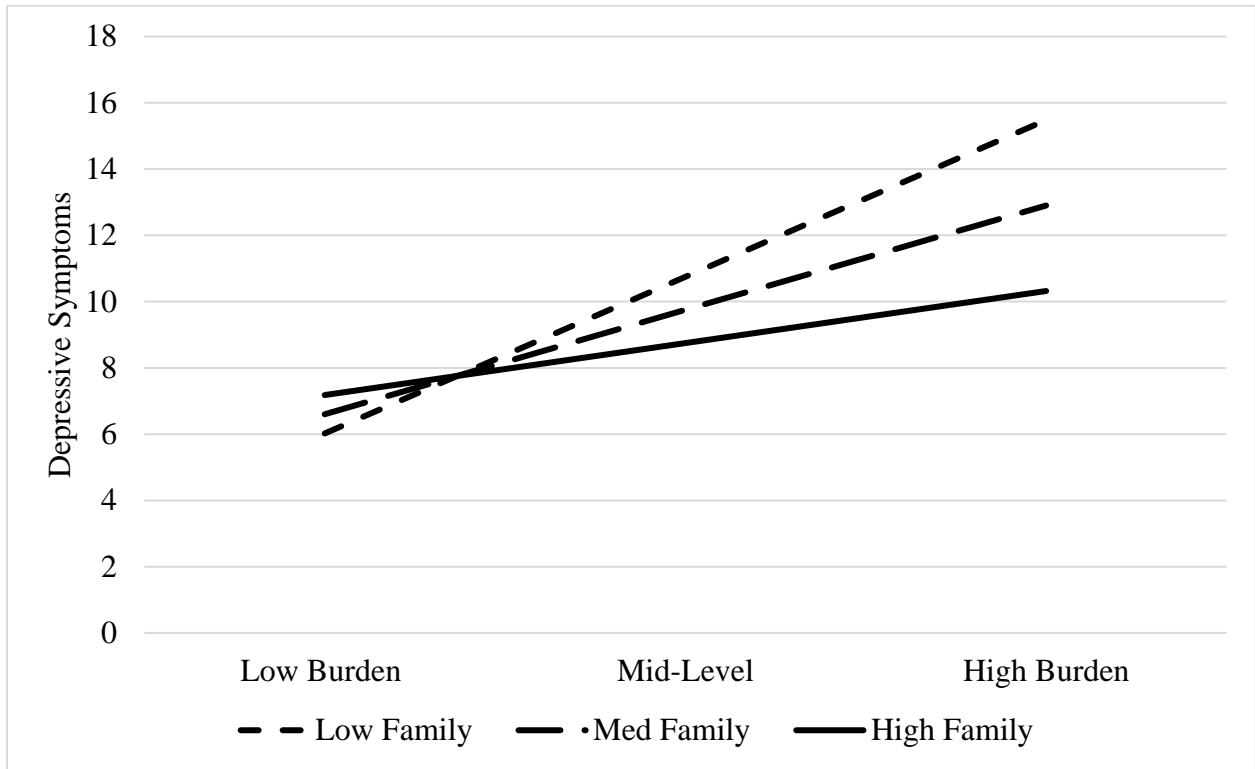


Figure 2



As a follow-up to these analyses, the analyses were conducted individually for each sex to determine if, in addition to the effects that emerged for the full sample, social participation and psychological well-being would moderate the effects of caregiver burden on the outcome measures for each of the sexes. A total of 24 analyses were conducted (12 for each sex), and only one significant interaction emerged. Step 3 of Table 11 shows that there was a significant interaction between subjective burden and friend participation predicting depressive symptoms for the men only. In order to evaluate the nature of the interaction, the effects of subjective burden on depressive symptoms were examined at three levels of friend participation, 1 SD below the mean, the mean, and 1 SD above the mean. Figure 3 shows that, consistent with expectations, the negative impact of subjective burden on depressive symptoms was smaller for fathers experiencing high rates of friend participation than for those with less friend participation. There were no other significant interactions between resources and burden variables for either sex or for individual parent groups by sex (i.e., women in the IDD parenting group, men in the SMI parenting group, and women in the IDD parenting group, and men in the IDD parenting group). The results of these analyses are presented in Appendices 1-5.

Table 11

*Caregiver Burden Predicting Depressive Symptoms Moderated by Social Participation and Psychological Well-Being for Fathers Only (N=172)*

Variable	B	SE B	$\beta$	t	B	SE B	$\beta$	t
<b>Step 1 Burden and Controls</b>								
Subjective Burden	0.22	0.09	0.21**	2.58	0.15	0.08	0.14*	1.94
Direct Care	1.54	1.75	0.08	0.38	1.43	1.52	0.08	0.38
Group	-0.44	1.52	0.02	0.26	0.38	1.34	0.02	0.29
Marital Status	-5.66	1.96	-0.23**	-2.88	-4.29	1.71	-0.17*	-2.51
R <sup>2</sup>			0.07***					
<b>Step 2 Social and PWB</b>								
Organizational					-0.02	0.10	0.06	-0.52
Friend					-0.09	0.21	-0.45	0.65
Family					0.38	0.24	0.11	0.12
Psychological Well Being					-0.22	0.03	-0.49***	-6.83
$\Delta R^2$							0.26***	
<b>Step 3 Interaction</b>								
Burden X Organization					-0.01	0.01	-0.03	-0.37
Burden X Friend					-0.05	0.03	-0.13*	-1.76
Burden X Family					-0.05	0.03	-0.12	-1.61
Burden X PsyWellBeing					0.00	0.00	-0.02	-0.29

Direct Care X Organization	0.03	0.26	0.01	0.12
Direct Care X Friend	-0.33	0.52	-0.06	-0.63
Direct Care X Family	1.07	0.57	0.17 <sup>a</sup>	1.92
Direct Care X PsyWellBein	-0.06	0.08	-0.06	-0.76
$\Delta R^2$				0.01***

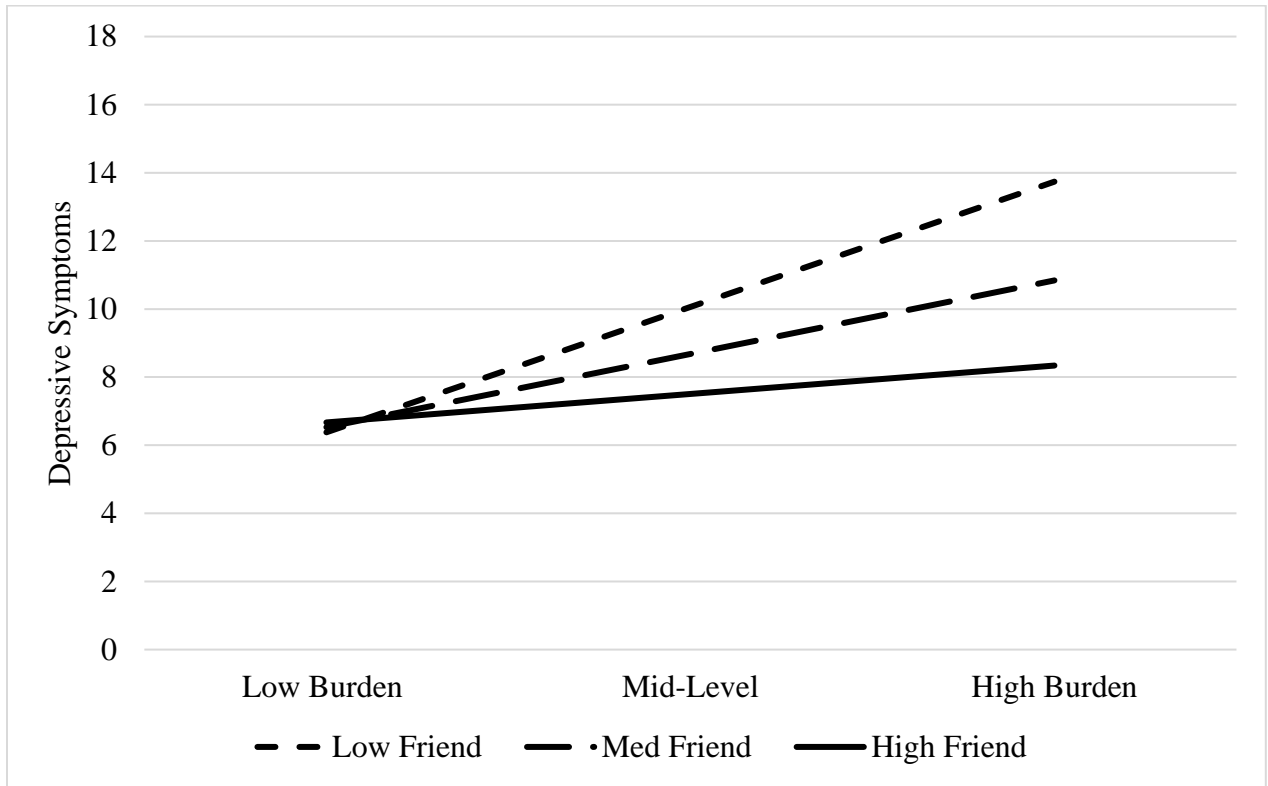
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\*p < .05. \*\*p < .01. \*\*\*p < .001.

a indicates an interaction that was *only* significant when force entered and not significant when entered stepwise.



Figure 3



Parent-group and co-resident differences in moderation.

Because of the limited findings for expected main effects and moderation, exploratory analyses were conducted to determine if other expected effects would occur with the separate disability groups, as indicated by three-way interactions between Caregiver Burden X Resources X Disability Group. The interactions were entered stepwise following all two-way interactions. No three-way interactions entered into the equation. Thus, these findings suggest that there were no two-way interactions between the burden and social participation variables that varied across the parent groups.

Three-way interactions also were evaluated as follow-up analyses to test whether moderation effects occurred only within the co-resident group as opposed to the non-co-resident group. The three-way interactions were Caregiver Burden X Resources X Co-Residence. With two caregiver burden variables, four resource variables, and three outcomes, a total of twenty-four three-way interactions were evaluated. Four significant three-way interactions were found. However, follow up analyses indicated that two of these interactions showed that effects of burden and co-residence status were dependent on levels of psychological well-being, and thus, were not relevant to the current hypotheses. Specifically, the significant 3-way interaction of Subjective Burden X Psychological Well-Being X Co-Residence predicting memory, and the three-way interaction of Direct Care X Psychological Well-Being X Co-Residence predicting depressive symptoms included differences in two-way interactions between Burden X Co-Residence, rather than Burden X Participation interactions being significant in the co-resident group but not in the non-co-resident group. Given that the significant 3-way interactions were not relevant to the proposed moderation effects, they were not probed further. However, the two other interactions were informative about the hypothesized associations. The interactions of Subjective Burden X Organization Participation X Co-residence predicting both health related quality of life and depressive symptoms were significant and the Burden X Participation interactions were significant in the co-resident group but not in the non-co-resident group.

Figures 4 and 5 show the significant interaction between subjective burden and organization participation predicting health related quality of life in the co-resident parenting group and in the non-co-resident group, respectively. As shown in Figure 4, for the co-resident group, the nature of the interaction was not fully consistent with organization participation

buffering the effects of caregiver burden. First, contrary to the expected buffer, the association between burden and lower quality of life was strongest under conditions of highest levels of organization participation. Furthermore, the crossover effect shown in Figure 4 indicates that the effects are more interpretable as a moderation effect of caregiver burden on the influence of organizational participation on HRQoL. Specifically, under the condition of low levels of burden, organization participation was a positive predictor of co-resident parent's HRQoL, consistent with expectations. However, under conditions of high levels of burden, organization participation was a negative predictor of co-resident parent's HRQoL. Thus, contrary to expectation, high levels of organization participation were associated with relatively low levels of HRQoL. Figure 5 shows there was no interaction between subjective burden and organization participation in non-co-resident parents.

Similar to the previous analyses, Figures 6 and 7 show the significant interaction between subjective burden and organization participation predicting depressive symptoms in the co-resident parenting group and in the non-co-resident group, respectively. As shown in Figure 6, for the co-resident group, the nature of the interaction was not fully consistent with organization participation buffering the effects of caregiver burden. First, the association between burden and higher depressive symptoms was strongest under conditions of highest levels of organization participation. Furthermore, the crossover effect shown in Figure 6 indicates that the effects are more interpretable as a moderation effect of caregiver burden on the influence of organizational participation on depressive symptoms. Specifically, under the condition of low levels of burden, organization participation was a positive predictor of co-resident parent's depressive symptoms. However, under conditions of high level of burden, organization participation was a negative predictor of co-resident parent's depressive symptoms. Here, high levels of organization participation were associated with relatively low levels of depressive symptoms, as expected by the original hypothesis 4, but only under conditions of high burden. Figure 7 shows there was no significant interaction between subjective burden and organization participation in non-co-resident parents.

Figure 4

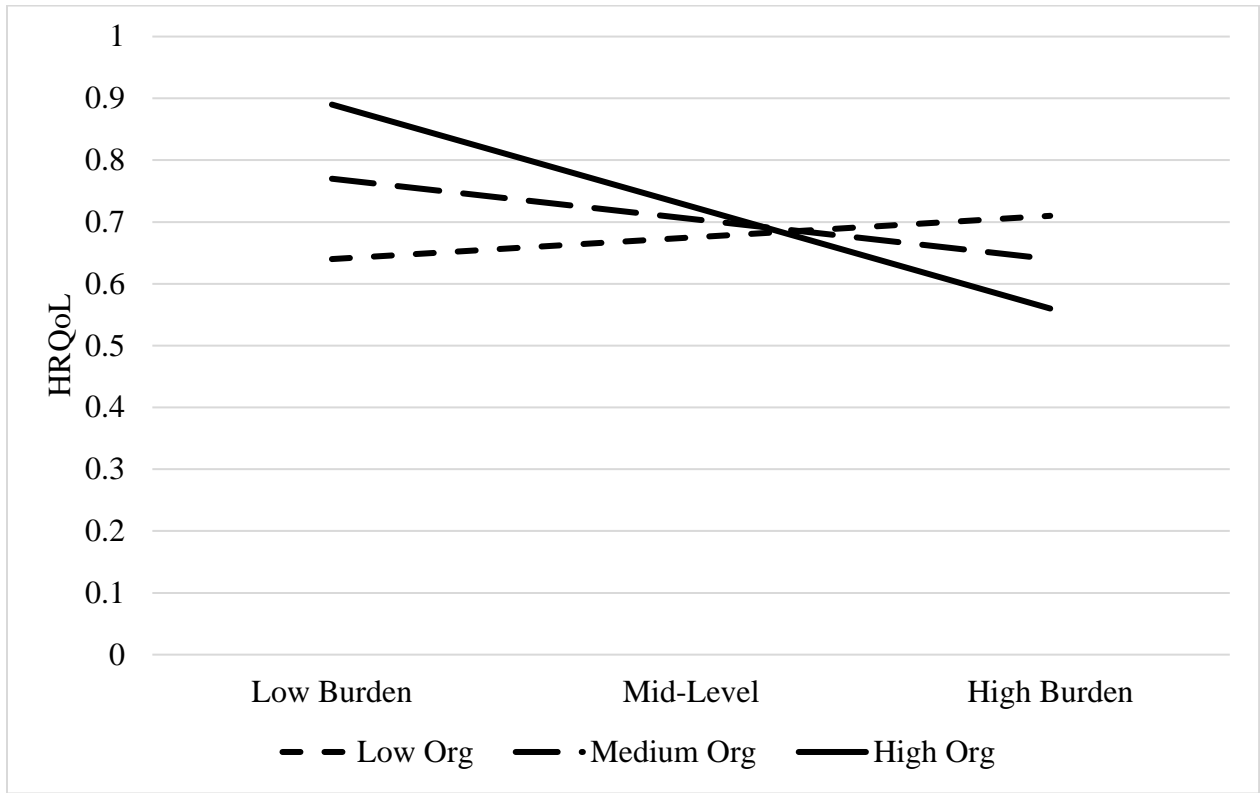


Figure 5

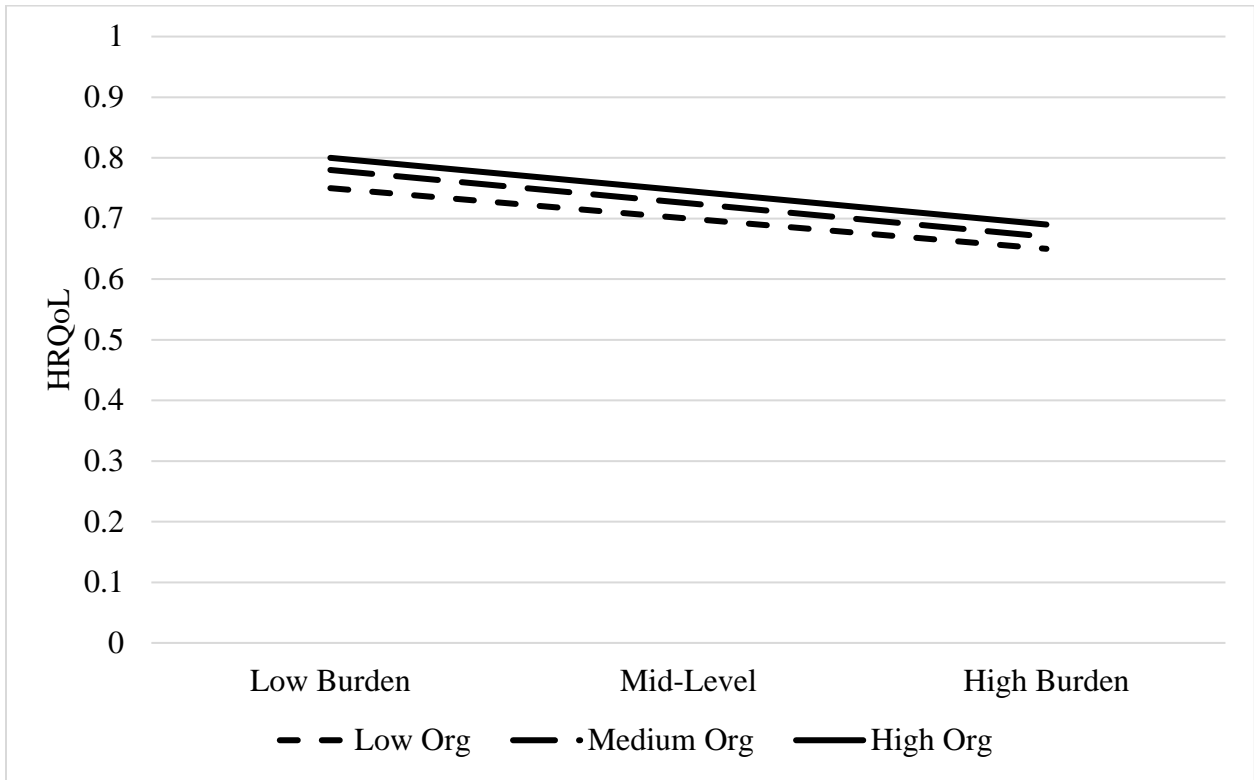


Figure 6

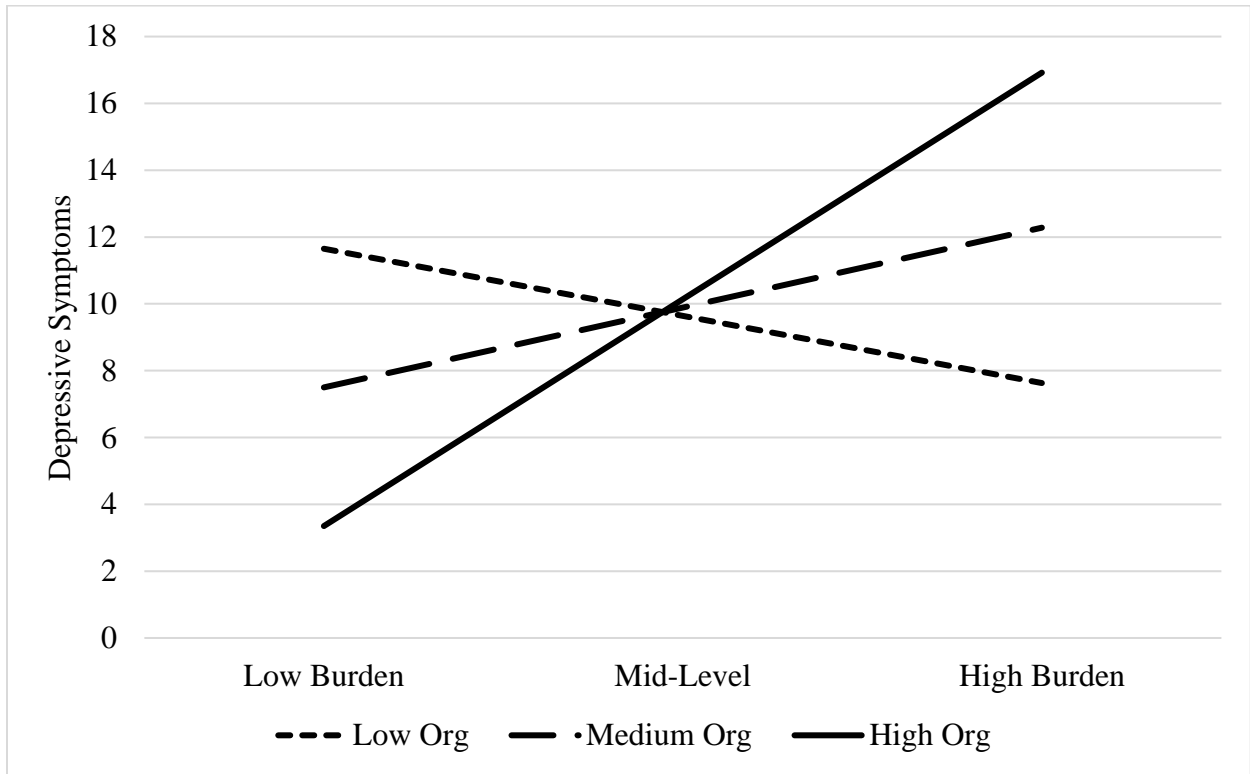
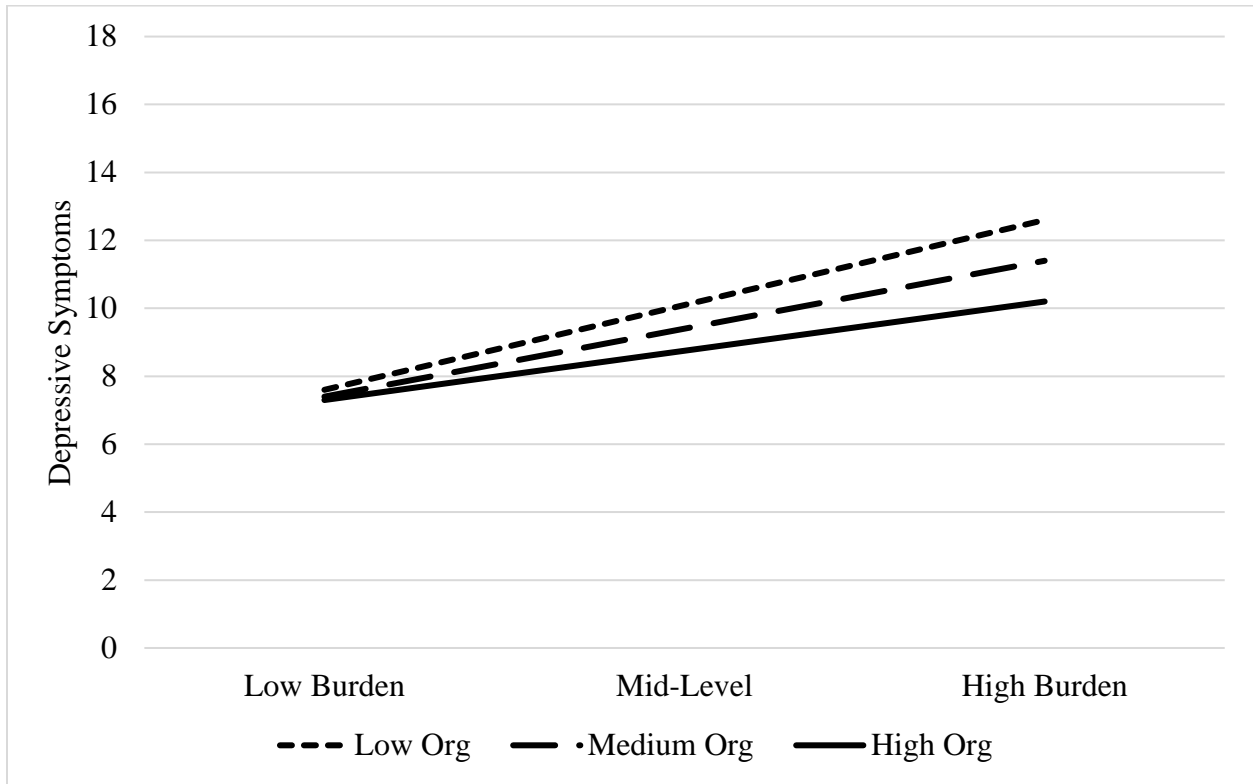


Figure 7



## Appendix 1

*Caregiver Burden Predicting Health Related Quality of Life Moderated by Social Participation and Psychological Well-Being in Mothers Only (N=246)*

Variable	B	SE B	$\beta$	t	B	SE B	$\beta$	t
<b>Step 1 Burden and Controls</b>								
Subjective Burden	-0.01	0.02	-0.18**	-2.91	-0.01	0.00	-0.15*	-2.51
Direct Care	-0.03	0.04	-0.04	-0.62	-0.03	0.04	-0.05	-0.83
Group	-0.04	0.04	-0.07	-1.04	-0.05	0.04	-0.09	-1.37
Marital Status	0.05	0.04	0.08	1.29	0.03	0.03	0.05	0.88
R <sup>2</sup>			0.04***					
<b>Step 2 Social and PWB</b>								
Organizational					0.02	0.03	0.05	0.13
Friend					-0.08	0.05	-0.09	0.07
Family					-0.06	0.06	-0.06	-0.18
Psychological Well Being					0.03	0.01	0.19***	3.70
$\Delta R^2$							0.07***	
<b>Step 3 Interaction</b>								
Burden X Organization					0.00	0.00	-0.01	0.10
Burden X Friend					0.00	0.00	-0.09	-1.11
Burden X Family					0.00	0.00	0.11	1.52
Burden X PsyWellBeing					0.00	0.00	-0.04	-0.64



Direct Care X Organization	-0.01	0.01	-0.09	-1.17
Direct Care X Friend	0.03	0.01	0.18*	2.23
Direct Care X Family	-0.01	0.02	-0.04	-0.54
Direct Care X PsyWellBein	0.00	0.02	0.01	0.16
$\Delta R^2$				0.01***

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\*p < .05. \*\*p < .01. \*\*\*p < .001.

## Appendix 2

*Caregiver Burden Predicting Health Related Quality of Life Moderated by Social Participation and Psychological Well-Being in Fathers Only (N=172)*

Variable	B	SE B	$\beta$	t	B	SE B	$\beta$	t
Step 1 Burden and Controls								
Subjective Burden	-0.01	0.00	-0.20*	-2.58	-0.01	0.00	-0.18*	-2.36
Direct Care	0.01	0.05	0.01	0.17	0.02	0.05	0.04	0.45
Group	0.01	0.04	0.02	0.25	0.02	0.04	0.03	0.36
Marital Status	0.06	0.06	0.08	1.10	0.03	0.05	0.04	0.56
R <sup>2</sup>			0.04***					
Step 2 Social and PWB								
Organizational					0.00	0.00	0.07	0.96
Friend					0.00	0.01	0.05	0.67
Family					-0.01	0.01	-0.07	-0.99
Psychological Well Being					0.00	0.00	0.30***	3.99
$\Delta R^2$							0.15***	
Step 3 Interaction								
Burden X Organization					0.00	0.00	-0.04	-0.47
Burden X Friend					0.00	0.00	0.16 <sup>a</sup>	1.94
Burden X Family					0.00	0.00	0.04	0.57
Burden X PsyWellBeing					0.00	0.00	-0.04	-0.45

Direct Care X Organization	0.01	0.01	0.07	0.23
Direct Care X Friend	0.02	0.02	0.24*	2.03
Direct Care X Family	-0.03	0.02	-0.17	-1.88
Direct Care X PsyWellBein	0.00	0.00	0.03	0.32
$\Delta R^2$			0.01***	

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\*p < .05. \*\*p < .01. \*\*\*p < .001.

a indicates an interaction that was *only* significant when force entered and not significant when entered stepwise.

## Appendix 3

*Caregiver Burden Predicting Health Related Quality of Life Moderated by Social Participation and Psychological Well-Being in Mothers Only (N=246)*

Variable	B	SE B	$\beta$	t	B	SE B	$\beta$	t
Step 1 Burden and Controls								
Subjective Burden	-0.01	0.03	-0.03	-0.53	-0.01	0.03	0.00	-0.06
Direct Care	0.05	0.50	0.01	0.10	-0.13	0.49	-0.02	-0.27
Group	0.52	0.49	0.08	1.06	0.41	0.48	0.06	0.86
Marital Status	-0.24	0.42	-0.04	-0.58	-0.39	0.41	-0.06	-0.94
R <sup>2</sup>			0.01					
Step 2 Social and PWB								
Organizational					0.04	0.03	0.08	1.11
Friend					-0.12	0.06	-0.14	-1.89
Family					-0.03	0.08	-0.02	-0.32
Psychological Well Being					0.03	0.01	0.19****	2.81
$\Delta R^2$							0.18****	
Step 3 Interaction								
Burden X Organization					0.01	0.00	0.08	1.04
Burden X Friend					-0.01	0.01	-0.12	-1.43
Burden X Family					0.00	0.01	0.02	0.29
Burden X PsyWellBeing					0.00	0.00	0.04	0.61

Direct Care X Organization	-0.03	0.08	-0.03	-0.31
Direct Care X Friend	0.16	0.15	0.10	1.11
Direct Care X Family	0.03	0.19	0.01	0.14
Direct Care X PsyWellBein	0.01	0.02	0.03	0.40
$\Delta R^2$			0.00	

---

\*p < .05. \*\*p < .01. \*\*\*p < .001.

## Appendix 4

*Caregiver Burden Predicting Health Related Quality of Life Moderated by Social Participation and Psychological Well-Being in Fathers Only (N=172)*

Variable	B	SE B	$\beta$	t	B	SE B	$\beta$	t
Step 1 Burden and Controls								
Subjective Burden	0.00	0.03	0.00	-0.02	0.01	0.03	0.02	0.25
Direct Care	0.31	0.48	0.05	0.64	0.36	0.48	0.06	0.74
Group	0.48	0.44	0.09	1.11	0.50	0.43	0.09	1.15
Marital Status	1.22	0.55	0.17*	2.22	1.07	0.55	0.15	1.94
R <sup>2</sup>			0.04*					
Step 2 Social and PWB								
Organizational					-0.01	0.04	-0.02	-0.22
Friend					-0.01	0.07	-0.01	-0.11
Family					-0.12	0.09	-0.11	-1.40
Psychological Well Being					0.03	0.01	0.18*	2.27
$\Delta R^2$							0.03***	
Step 3 Interaction								
Burden X Organization					0.00	0.01	-0.06	-0.63
Burden X Friend					0.00	0.01	0.02	0.25
Burden X Family					0.00	0.01	-0.02	-0.19
Burden X PsyWellBeing					0.00	0.00	-0.14	-1.69

Direct Care X Organization	0.13	0.09	0.18	1.45
Direct Care X Friend	0.06	0.18	0.04	0.35
Direct Care X Family	0.12	0.19	0.06	0.61
Direct Care X PsyWellBein	0.03	0.02	0.13	1.38
$\Delta R^2$			0.00	

---

\*p < .05. \*\*p < .01. \*\*\*p < .001.

## Appendix 5

*Caregiver Burden Predicting Depressive Symptoms Moderated by Social Participation and Psychological Well-Being in Mothers Only (N=246)*

Variable	B	SE B	$\beta$	t	B	SE B	$\beta$	t
Step 1 Burden and Controls								
Subjective Burden	0.18	0.06	0.17**	2.76	0.12	0.06	0.12*	2.14
Direct Care	0.24	1.25	0.01	0.19	0.35	1.07	0.02	0.32
Group	1.06	1.23	0.06	0.87	1.71	1.05	0.10	1.63
Marital Status	-1.73	1.05	-0.11	-1.65	-1.05	0.90	-0.06	-1.17
R <sup>2</sup>			0.05**					
Step 2 Social and PWB								
Organizational					0.13	0.07	0.10	0.13
Friend					-0.10	0.13	-0.04	0.07
Family					0.30	0.17	0.10	-0.18
Psychological Well Being					-0.21	0.02	-0.55****	9.63
$\Delta R^2$							0.24****	
Step 3 Interaction								
Burden X Organization					-0.01	0.01	-0.07	-1.21
Burden X Friend					0.02	0.02	0.07	1.02
Burden X Family					-0.05	0.02	-0.14 <sup>a</sup>	-2.03
Burden X PsyWellBeing					0.00	0.00	0.02	0.27



Direct Care X Organization	0.16	0.18	0.06	0.89
Direct Care X Friend	-0.26	0.32	-0.06	-0.82
Direct Care X Family	-0.05	0.40	-0.01	-0.13
Direct Care X PsyWellBein	0.01	0.05	0.01	0.10
$\Delta R^2$			0.00	

---

\*p < .05. \*\*p < .01. \*\*\*p < .001.

a indicates an interaction that was *only* significant when force entered and not significant when entered stepwise.

## Discussion

The purpose of the current study was to evaluate the effects of lifelong stress on aging parents of adult offspring with either intellectual and developmental disabilities or severe mental illness. The hypotheses were that caregiver burden would have adverse effects on the physical, cognitive, and psychological functioning of these parents, and that interpersonal and intrapersonal resources would act as protective factors against the negative effects of caregiver burden. The study also tested several preliminary hypotheses about possible subgroup differences in burden, resources, and functioning depending on the type of disability for the offspring and the circumstances of the parents co-residing with the offspring or not. The findings provided only minimal evidence of subgroup differences, and partial support for the expectations about the predictive effects of burden and resources. Moreover, they also suggested that there are circumstances under which social resources might add to stress in ways that were not anticipated. In this way, the findings partially supported the general stress and coping framework, but also suggested revisions that might be unique to parents at this stage of life under these caregiving circumstances.

### Subgroup Differences

There was little support for the hypotheses about more difficulties and fewer resources for the parents of adult offspring with severe mental illness as opposed to offspring with developmental disabilities. Specifically, the hypotheses proposed that these parents would show relatively higher rates of caregiver burden, have relatively lower functioning in physical health, memory, and depressive symptoms, and would report relatively fewer resources across organization, family, and friend participation and psychological well-being. The hypothesis was justified by evidence indicating that mental illness in an adult offspring is associated with impaired ability to consistently and appropriately engage in typical functional and occupational activities (Cucciare, 2008), and thus would be a particular source of poor functioning for their parents who provide care. The hypothesis was also justified by previous studies that have examined the differences between the groups in midlife and early old age and have found that parents of adult children with mental illness report greater levels of caregiver burden (Seltzer et al., 2004), poorer self-reported health (Magaña et al., 2004), and poorer psychological functioning (Ghosh et al., 2012) compared to parents of offspring with intellectual and

developmental disabilities. However, the current findings did not support the hypothesis in that the groups did not significantly differ in the expected direction on any of the variables in the study.

The finding that parenting groups did not significantly differ in the expected direction on any of the variables suggests that parents of adult offspring with disabilities and long-term illnesses may be more similar in functioning in old age than they are in earlier ages. Specifically, there may be a convergence of experiences between the two groups of parents as they reach old age. Yet, research has also suggested that the differences between the two groups in earlier ages may be due to the later onset of mental illness and its cyclical nature (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004) which may cause parents of adults with severe mental illness to live with greater uncertainty (Rolland & Werner-Lin, 2006) than parents of adults with disabilities, whose functioning is relatively stable (Marsh, 1992). It is possible that by later life these differences fade away, and the experiences of the parents in the two groups are similar given that parents of adults with severe mental illness have had more time to adjust. Specifically, now that the adult offspring are at middle age, their behavior problems may abate and the perceived uncertainty that the parents were living with may become more predictable and manageable. For example, Harding et al. (1987) followed patients with severe mental illness over 30 years and found that over half of the patient's symptoms improved over time. Further, Lewinsohn, Klein, & Seeley (1995, 2000) found that many people diagnosed with bipolar disorder during their adolescent years remit in their early 20s and that many of those who remit do not experience additional episodes in adulthood. In addition, multiple longitudinal studies have found that those diagnosed with bipolar disorder in childhood or adolescence often show little to no symptoms in their adult years (Birmaher et al., 2006; Geller, Tillman, Craney, & Bolhofner, 2004). Thus, it may be that the individuals in the SMI group are improving over time rather than those in the IDD group becoming worse over time.

Furthermore, the two variables that did show differences across the groups, memory functioning and providing direct care, were in the opposite direction than expected, with better memory functioning and less direct care provided by the parents of offspring with SMI. The finding that parents in the SMI group had significantly higher IQ scores than those in the IDD group is especially striking given that first degree relatives of people with SMI have been found

to have lower than average cognitive scores (Snitz, MacDonald, & Carter, 2006). The higher number of parents in the IDD group that provide direct care to their children may be due to the higher rates of co-residence in that group. This finding may be bidirectional in nature.

Specifically, offspring that require more direct care may be more likely to remain at home with their parents, and offspring that remain at home with their parents have more opportunities to receive the direct care. Further, the higher mean memory functioning scores in parents in the SMI group may be a result of the lower rates of direct care. Specifically, providing high rates of direct care may account for more stress which in turn may cause poorer short term memory functioning chronic stress is associated with low memory and physical functioning in old age, especially in parents of children with disabilities and severe, long-term mental illnesses (Marin, et al., 2011; Brehaut et al., 2004). These findings may also indicate that the parents of adults with SMI have adjusted to their life circumstances.

The hypothesis that co-resident parents of adult offspring with developmental disabilities and severe mental illness would show higher rates of caregiver burden, lower functioning in physical health, memory, and depressive symptoms, and would report fewer resources across organization, family, and friend participation and psychological well-being than non-co-resident parents was also not generally supported. Specifically, the residency groups did not significantly differ on most of the variables in the study, with the exception of family participation and the providing of direct care to the offspring. These finding also suggest convergence of experiences for parents as they reach old age in areas that showed differences in earlier life stages. For example, using the same cohort of parents of adult offspring with disabilities, Seltzer et al. (2011) found that the mean number of depressive symptoms for co-resident parents was 8.8 while non-co-resident parents averaged 7.7 depression symptoms when the parents were in their early to mid-60s. In the current study, the mean depressive symptoms for co-resident group was  $M = 9.96$ , and the mean for the non-co-resident group was  $M = 9.39$ . These overall increases are consistent with other studies have shown that depressive symptoms are more common in elderly individuals and the higher frequency is explained by factors directly associated with aging, including more physical difficulties, decreasing cognitive capabilities and lower socioeconomic status than at earlier ages (Blazer, 2000). Taken together, the findings support the idea that old age may be a more homogeneous for parenting adult offspring with different types of limitations.

Consistent with the hypothesis, the co-resident parents had significantly lower family participation scores and higher rates of providing direct care to their child than the non-co-resident parents. The finding that co-resident parents have significantly less family participation than non-co-resident parents is consistent with previous research (Seltzer et al., 2011). Higher rates of direct caregiving the co-resident parents provide to their adult offspring may have a compounding effect, leading to even greater vulnerability to the effects of caregiver burden. These two circumstances may be associated with each other as well. Specifically, family participation likely includes typically developing adult children that can help provide direct care to their sibling with the disability, though it is unclear whether or not the relatives with whom they are receiving support live in the same household as the respondent. However, being cut off from family and other adult children may lead to greater need for the parent to provide direct care for the adult offspring with disability or mental illness. In all, despite the similarities between the groups of co-resident and non-co-resident parents, the differences that were found may make co-resident parents more vulnerable the effects of caregiver burden and more susceptible to its deleterious effects.

#### Prediction of Functioning

The results supported the hypothesis that greater self-reported caregiver burden would significantly predict poorer health related quality of life and more depressive symptoms. This finding is consistent with other literature that has shown that many caregivers of persons with various disabilities and conditions report high rates of burden (Lawton et al., 1991) which negatively affects their health in old age (Schulz et al., 1995, Pinquart & Sorensen, 2003, Vitaliano et al., 2003). However, the current study is the only known study that has examined caregiver burden, health related quality of life, and depressive symptoms at old age both in parents of adult offspring with intellectual and developmental disabilities and parents of adult offspring with severe mental illness.

The findings highlight the differences in the meaning and consequences of subjective and objective burden as measured in this study. Direct care is whether or not the parent is taking time to provide day to day care to their child, which includes helping the offspring with getting dressed, grooming, shopping, transportation, chores or other activities. The subjective burden variable used in the study shows how much disruption the parents perceive in terms of

resentment, feeling overwhelmed, lack of time for themselves, stress, embarrassment, guilt, helplessness, anger, and regret (Zarit et al., 1980). That is, subjective burden is how disruptive the child is to the lives of the parents and the parents' psychological reactions to the objective burden (Magliano et al., 1998). Thus, the findings suggest that the negative impacts on physical and psychological health may be a result from these perceptions and feelings of distress rather than simply allocating time to provide for the offspring. Perhaps some parents who provide care do not perceive disruption from caring for their child. That is, perhaps providing direct care gives some parents a sense of agency and control in being able to do something about their circumstances. In contrast, subjective burden may be indicative of a sense of helplessness in the face of the child's problems. Accordingly, this type of helplessness in the face of stress has been associated with negative physical and psychological consequences in elderly individuals (Lachman, Neupert, & Agrigoroaei, 2011). Further, some parents report experiencing subjective burden in the context of providing direct care to the offspring, and other parents report subjective burden when not providing direct care. As such, subjective burden is truly the personal interpretation of the parents' experiences regardless of whether or not they are providing direct care to their offspring.

Among the resources, psychological well-being was a consistent predictor of all of the outcomes. Similarly, previous research in old age and in earlier life shows the wide-ranging benefits of psychological well-being (Pressman & Cohen, 2005; Boehm & Kubzansky, 2012). These findings are a strong example of the benefits of being able to maintain high levels of psychological well-being despite being in a generally stressful life circumstance. Many parents of children with disabilities have been found to successfully adapt, and even thrive, despite the additional stress and caregiving demand (Bayat, 2000; Hastings & Taunt, 2002). Many of those positive adaptations these parents make include maintaining positive outlooks, which predict many positive outcomes (Greeff & Nolting, 2013). These positive outlooks are likely reflected in psychological well-being that takes into account the person's level of self-acceptance, positive relations with others, autonomy, environmental mastery, purpose in life, and personal growth. Thus, being able to maintain psychological well-being may help parents adapt more readily to the challenges they face, even if they have been caring for many years and have reached old age. Also of importance, these findings add caregiving of adult offspring with special needs to the growing literature that shows factors and vulnerabilities in aspects of well-being among older

compared to young or midlife adults (Ryff, 1989; Ryff & Keys, 1995; Clarke, Marshall, Ryff, & Rosenthal, 2000). It is also important to note that there is some overlap between the well-being measure and depression. This type of overlap does not occur among the other variables and may limit how these specific findings can be interpreted. For example, having a sense of purpose in life and engaging in activities that promote personal growth may be antithetical to depression. However, the ability to maintain a sense of well-being is an important construct that is distinct from the other outcomes, and may even precede them. Psychological well-being also captures positive adaptation to life circumstance as well as general lack of maladaptation. Further, the prediction of all three outcomes, including health and cognitive functioning, demonstrates that maintaining psychological well-being could pave the way for positive functioning in old age. It is also important to acknowledge that these findings may also be demonstrating effects in the opposite direction. Specifically, those individuals that are of good physical health may be more apt to report that they are experiencing less burden. Further, those that are of good physical health may also be more physically equipped to deal with potentially burdensome life events and circumstances.

Family participation was also found to be important for all parents in the study in terms of predicting better psychological functioning. Specifically, high levels of family participation were associated with low levels of depressive symptoms in all parents of adult offspring with disabilities or long-term illnesses. Other studies in old age have also demonstrated that participation with family members and overall closeness within a family are positively associated with happiness (Lelkes, 2006; Powdthavee, 2008; Leung et al., 2013; Serovich et al., 2001). These findings are also consistent with research showing that being isolated from family members has been associated with higher depressive symptoms in parents of adults with schizophrenia (Ghosh & Greenberg, 2012). It is also possible that the findings are indicative of a bidirectional relationship between family participation and depression. Specifically, those parents that are more depressed may be more inclined to remain socially isolated from their family members. In turn, those same parents that are now more socially isolated may experience greater depression. That is, the association between these variables might reflect the well-established interplay of depression and social withdrawal seen across all age groups (Santini, Koyanagi, Tyrovolas, Mason, & Haro, 2015).

In addition to contributing directly to better functioning, the findings also supported the hypothesis that family participation would buffer the negative effects of caregiving burden on depression. Specifically, the negative impact of caregiving on depression was smaller for parents experiencing high rates of family participation than for those with little family participation. This finding is consistent with the stress buffering model where social participation buffers the effects of stress. Studies have shown that positive emotions and attitudes toward members of their family increase as people age (Charles & Piazza, 2007) and that social contacts with family members build intimacy within the family that is important to maintaining a sense of self-worth (Charles & Carstensen, 2010). Further, the majority of parents in the current study had other children in addition to those with IDD and SMI. As such, it is likely that family participation involved contact with their other adult children in particular. However, it is not explicitly stated whether or not the families of these participants live in the same households as the respondents. As such, some of the respondents may be including typically developing adult offspring, able bodied spouses, or other relatives that reside in their home and are providing care or assistance to them or the offspring with special needs. Given that old age is generally a time when elder parents transition into receiving more care than giving it (Angel, 2011), social participation with family members may be indicative of passing on caregiving responsibilities for the offspring with disabilities to the other adult offspring. Those parents that are experiencing the most burden are also likely to benefit the most from reduced managing of ongoing day-to-day needs of the adult offspring with disabilities or long-term illness. Further, perhaps without family participation and the support that may come from it, parents may have difficulty meeting their adult offspring's immediate needs and planning for long-term care at a time when the parents struggle with their own functional limitations.

However, family involvement was not a moderator of stress in predicting the parent's health related quality of life or their memory functioning. It is possible that changes in physical health and memory may take longer to develop than changes in depressive symptoms. Specifically, this study used concurrent predictors and moderators which may have more direct associations with current depression given that depression is reactive to current circumstances (Kraaij, Arensman, & Spinhoven, 2002), and, thus, may be more sensitive to daily stress. However, studies have shown that health and cognitive functioning might show delayed effects of stress and burden (Blazer, 2000). However, friend participation moderated stress on some of



the outcomes. As such it may be that family participation is more stable than friend participation over time making family participation less sensitive to changes in concurrent predictors, such as the ones used in the current study.

Friend participation is also consistent with the stress buffering model in that the results suggest friend participation buffers the negative effects of burden on health related quality of life. Specifically, consistent with a buffering effect, the results show a pattern in which the negative effects of burden on health are only apparent under circumstances of low friend participation, but not when friend participation is relative high. Studies have shown that ties to friends can provide companionship and emotional support to parents (Lapierre & Keating, 2013) and the frequency of visits with friends is strongly related to overall well-being in older adults (Ritchey et al., 2001). We can speculate that companionship and emotional support may alter a person's internal sense of well-being. Perhaps friends also are able to provide tangible resources, such as opportunities to become aware of helpful resources that could promote good health (Liebler & Sandefur, 2002). To this end, Berkman (2001) found that positive social interactions promote the exchange of health information and encourage advantageous health related behaviors such as regular visits to primary care physicians, decreased alcohol use, and more nutritious diet. Friends may facilitate the sharing of health information which may lead to better health. Overall, it appears that maintaining high levels of relationships with friends may be one way that parents may be able to buffer the effects of burden and adapt to their current circumstances.

Friend participation was also found to buffer the negative effects of burden on depression, but this effect was shown only for the fathers in the study. Specifically, the results show a pattern in which the negative effects of burden on depression are only apparent under circumstances of low friend participation in the fathers, but this pattern was not seen in the mothers in the study. These findings may indicate that men may be able to emotionally adapt to difficult circumstances only with the right support. Van Grootheest, Beekman, van Groenou and Deeg (1999) found that widowhood was more strongly associated with depression in elderly men than women. This loss of support and difficult life circumstance may be particularly deleterious for elderly men in that men may be more isolated from other friends. It is also possible that men's friendships are more activity oriented than emotional support oriented, thus leading to

more activity out the home and having outside interests. These activities may be protective against the negative impacts of stress. Similarly, the findings of the current study indicate that maintaining support of others may buffer against depression in these men as they adapt to their current circumstances, and a loss or lack of support may make that adaptation difficult.

The findings associated with the organization participation variables may be the most striking of the current study. The three-way interactions indicated that organization participation was most impactful only under certain circumstances, and the patterns of the findings showed that rather than reducing the negative effects of burden, as expected, its impact seemed to be either enhanced or reversed depending on the person's level of perceived burden. Specifically, organization participation had a positive impact on co-resident parents with low levels of burden, with higher organization participation being associated with higher levels of health related quality of life and fewer depressive symptoms. However, organization participation had the opposite effect for co-resident parents with high rates burden. Specifically, in co-resident parents with high rates of caregiver burden, high levels of organization participation were associated with lower levels of health related quality of life and higher rates of depressive symptoms. Further, in non-co-resident parents, organization participation worked in the expected direction, with higher levels of organization participation buffering the negative effects of caregiver burden on depressive symptoms.

The unexpected association of organization participation with poor functioning for the co-resident parents experiencing relatively high levels of burden raises the question of whether this form of social participation actually adds to the stress of the highly stressed parents. Indeed, other research has indicated that the benefits of some types of social participation have limits. However, the other studies have not directly examined organizational participation, making it difficult to make direct inferences from other research. Specifically, Ang and Malhotra (2016) examined older adults ages 62 to 97 years and found that high rates of social participation with close friends and family members, and receiving social support from them, were associated with low levels of depressive symptoms in some of the participants. Yet, in other participants in the study the opposite was true with, high amounts of social participation being associated high rates of depressive symptoms. The authors found that a sense of control over one's life determined whether social participation would be beneficial or harmful. Specifically, some of the

participants interpreted receiving social support as an indicator of their own diminished capacity to care for themselves and were thus becoming dependent on others. That loss of perceived control over their own lives and budding dependence on others counteracted the potential positive benefits of social participation and subsequently led to higher depressive symptoms. Similarly, Silverstein, Chen, and Heller (1996) found that too much social support for older adults can erode their confidence as their perceived ability to care for themselves decreases. It is important to note that these constructs are not identical in that the previous studies examined the negative effects of family and friend social support in old age, which are somewhat different constructs from organization participation. However, these previous findings show how a presumably positive situation (i.e., social support) may be interpreted negatively by older adults and it is possible that organizational participation has negative connotations as well.

An alternative explanation is that the negative effects of organization participation may come through role overload and role conflict (Coverman, 1989). Role overload is defined as having too many role demands and too little time to fill them (Baruch et al., 1985) whereas role conflict is the extent to which the person experiences pressure within a role that simultaneously puts additional pressure on another role (Kopelman et al., 1983). Both of these constructs have been found to lead to high levels of depressive symptoms (Coverman, 1989, Fong, 1990). Both role overload and role conflict may simultaneously explain the findings that high levels of organization participation led to high levels of depressive symptoms and low levels of health only in co-resident parents with high burden. Co-resident parents already have a very important responsibility to care for their child. They maintain a role of caregiver at a time when many parents of typically developing offspring without mental illnesses are no longer active in a caregiver role. These parents are also reporting that the care they provide their child is highly burdening, thus indicating their caregiver role is stressful. This unique and stressful role is likely to put pressure on their day to day living. The addition of more roles in organizations might increase the pressure on their other roles, and simultaneously might take time away from their caregiver responsibilities. These experiences may be very different from parents with the same roles who report low levels of burden. Indeed, the parents who reported lower burden seemed to benefit from organizational participation in positive, expected ways. These parents may be able to enjoy the positive benefits of participating in organizations given that their roles may be less likely to result in feelings of being overwhelmed or conflicted about obligations given that their

offspring may not disrupt their lives to the same extent. Thus, having too many roles in addition living with an adult with an adult offspring with disabilities or long term mental illness who causes disruption to the parents may contribute to greater depressive symptoms and poorer health. It is also possible that organization participation is an attempt for parents who are highly stressed and not doing well to find respite out of the home. In this way, there may be a bidirectional relationship in that the many roles may be leading to poorer functioning, yet functioning poorly may also be leading parents to seek out more organizations or roles.

There are many implications for intervention. A review of interventions that specifically target social isolation in elderly people by Dickens, Richards, Greaves, and Campbell (2011) showed that interventions that offer social activity and/or support within a group format were most effective. The review also found that interventions in which the elderly people were active participants was also more likely to be effective than other types of interventions in which they were passive observers. However, the findings of the current study show that too many organizations for certain high burdened parents may be associated with poorer functioning. As such, it may be important for highly burdened parents living with their adult offspring to increase their participation in social activities and support groups and decrease their participation in other organizations. Also, in a review of caregiver burden by Adelman et al. (2014) it was suggested that caregivers experiencing deleterious effects of burden should be encouraged to function as a member of a care team for their care recipient, be provided with education and information, use technology as a form of gaining support through online forums, and should be given information on the assistance and services that are available to them. The findings also point to the need for more services to be available to these parents which may include home visits from professional caregivers as a form of support which has been shown to be effective for elderly people with few social contacts (Cattan, White, & Bond, 2005).

### Limitations

The current study had methodological limitations that are important to consider when interpreting the findings. The memory measure used in the study was administered over the phone which differs from how it was originally validated. Specifically, the measure was taken from an individually administered test that was designed and validated when given live, in a sequestered testing setting. Thus, the accuracy of this form of administration is unknown and

may have poor reliability and validity. As such, it is possible that the limited findings for the memory functioning variable are due to the non-standardized administration. There was also a lack of racial and ethnic diversity in the sample, with essentially all of the Wisconsin parents being White. As such, it is unknown whether the findings would generalize to other ethnic/cultural groups, as approaches to aging and caregiving differ across cultures. Among many cultural differences, more collectivist cultures may assist parents in caregiving throughout the life course, thus decreasing their burden. Conversely, people in other cultures may be more prone to self-isolate when raising a child with a disability, potentially increasing the parent's burden. Another limitation of the study was that information on the severity of offspring's disabilities or mental illnesses was not available in the WLS and, thus, could not be taken into account in these analyses. It is possible that the presence of relatively severe disability for the offspring may be the underlying reason for co-residence and may also increase the parent's depressive symptoms. However, without a measure of disability severity, it is not possible to determine if this factor accounted for the findings of the study. Also, all participants included in the study were of sufficient psychological functioning to complete the entire WLS follow up study with both in-person and mail-in components. Individuals with the highest burden, poorest health, lowest cognitive capacities and/or highest levels of depression, may have opted out of the follow up study or were unable to complete one of the components of the study (i.e., in person or via mail), thus resulting in exclusion from the current sample and limiting the representativeness of all parent of adult offspring with disabilities and mental illnesses. Also, given that this is the first study that has examined these parenting groups in their seventies, it is difficult to determine if these findings would be replicated. Yet, the longitudinal predictors of the outcomes used in the study are unknown. Also, a comparative sample of parents of typically developing offspring was not used in the current study because many of the measures were only given to parents of offspring with disabilities and mental illness. Thus, it is unknown how the experiences of these parents differ from parents of typically developing offspring. In addition, another limitation of the study is the potential shared measurement variance between the subjective predictors (e.g., Zarit Burden Interview as a measure of caregiver burden) and subjective outcomes (e.g., CES-D as a measure of depressive symptoms). The amount of overlap between the measures may partially explain the significant findings which is a limitation of the study. The findings of the current study should be interpreted in light of the shared variance and the recognition that a

higher percentage of subjective and potentially overlapping) measures were significant than objective measures. It is also important to note the possibility that the effects found in the current study may work in the opposite direction than expected. Findings must be interpreted within the context of potential opposite effects. Another potential limitation of the study was the large amount of missing data that was generated. Though the decision to replace missing data fell within the limits of best statistical practices, relatively large amounts of missing data present increased potential for error. Another limitation of the study was the lack of correction for multiple analyses. The decision to control for multiple analyses is often a trade-off between the cost associated with a false positive versus the benefit of uncovering novel information (Noble, 2009). Given the large scope of the current study, corrections for multiple analyses may have rendered significant findings impossible to detect, thus multiple analyses were not controlled for in order to increase the likelihood of identifying novel information. However, the increased likelihood of finding false positives in the current study presents a limitation. Lastly, it is acknowledged that many of the current study's findings were non-significant. As such, the significant findings must be interpreted within the context of being a small minority of the overall findings of the current study.

#### Future Directions

Future research may further examine the possibility of role overload and role conflict in co-resident parents with high burden. It is possible that co-resident parents with high burden may be susceptible to role overload when examining other roles such as caring for a spouse or remaining employed into old age. It may also be important to use the continuous measure of direct care hours in the intellectual and developmental disabilities sample, given the low rates of direct care in the severe mental illness sample. It may also be better to examine a comparison group to determine if the two groups differ on the variables asked of all participants in the WLS such as the outcome variables and the moderators. Comparisons on other measures would be useful for understanding how functioning for these parents relates to typical patterns. In addition, given that this study focused exclusively on amount of social participation parents engage in, future research may focus on the nature of quality of the participation as a predictor of functioning.

In conclusion, the current study both partially confirms expectations and provides new insights about caregiver burden and resources in parents of adult offspring with intellectual and developmental disability and severe mental illness, and the effects these factors have on their parents' functioning in old age. Consistent with previous research, protective factors include maintaining psychological well-being and family participation, which may protect against the onset of depressive symptoms and health problems in old age. A potentially important new finding is that co-resident parents in old age that are highly burdened appear to be the most susceptible to the negative effects of high participation in organizations. These highly taxed parents may be part of organizations out of necessity or a belief that doing so may alleviate their stress. Yet, over time these parents with the additional role of living with an adult child that is burdensome, may become overwhelmed with their responsibilities. Only through continued replication of studies on elderly parents of offspring with disabilities and long-term illnesses can concurrent predictors and risk factors of their functioning such as role overload, caregiver burden, and social isolation be determined. Implications for intervention may include highly burdened parents reducing organization participation while increasing activity in disability-related support groups and potentially being provided home visits by professional caregivers.

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