MODERATORS OF THE RELATIONSHIP BETWEEN FAMILY CAREGIVER

PROXY RATINGS AND PERSON WITH DEMENTIA SELF-RATINGS OF

QUALITY OF LIFE

by

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Dedication

I dedicate this work to those closest to me, my family.

To my mother; a woman who was willing to sacrifice anything for the happiness and well-being of her family and friends. It was with your love and support that I sought to pursue higher education in mental health and health sciences. I miss you.

To my loving wife; thank you for being you. You have been so patient and understanding during this entire process. Your energy and zeal for life have brightened even my darkest days. I will forever be indebted to you. I love you.

To my father; a man who will take any burden on his shoulders for the sake of family. You have supported me in more ways than I can fathom. Every challenge I have faced you have ruminated upon it as though it were your own. I idolize you.

To my brother; a man who has always placed my concerns and challenges above his own. Thank you for our deep and lengthy conversations that challenge and enlighten me. You truly do take after our mother. I could not have asked for a better brother. I cherish you.

I would not be here without any of you.

Abstract

As the dementia spectrum lacks any viable cure, quality of life is typically regarded as an essential measure of assessing the clinical course and evaluating interventions. With caregivers typically providing this rating to health professionals, the literature has noted inconsistencies between caregiver and person with dementia (PwD) ratings of quality of life and suggested several factors may moderate the rating relationship. To investigate this, an intraclass correlation coefficient was calculated to observe rating agreement and moderator regression analysis was conducted to explore potential moderators. Potential moderators of caregiver burden, caregiver age, caregiver income, PwD IADLs/ADLs, PwD education, PwD cognitive impairment, PwD depressive symptom severity, PwD behavioural symptom severity, as well as relationship between caregiver and PwD. Utilizing secondary data from 107 recruited dyads, analyses conducted found fair agreement between caregivers and those with dementia while none of the hypothesized factors were found to moderate the rating relationship.

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List of Abbreviations

Caregiver Burden Inventory	CBI
Cornell Scale for Depression in Dementia	CSDD
Disability Assessment for Dementia	DAD
Functional Assessment Staging	FAST
Person with Dementia	PwD
Montreal Cognitive Assessment	MoCA
Quality of Life in Alzheimer's Disease	QOL-AD
World Health Organization	WHO

Chapter 1: Introduction

This chapter discusses and introduces the research problem of the thesis and relevant research questions. The main problem this project seeks to address is the reported inaccuracies of proxy ratings provided by caregivers on behalf of persons with dementia (PwDs). In particular, the study focuses on proxy ratings of wellbeing and quality of life. The research questions that guide this thesis are as follows: (1) What is the level of agreement between proxy raters and PwD's self-ratings of quality of life? (2) What factors moderate the relationship between proxy ratings and PwD ratings?

Problem Statement

Dementia is a profoundly disabling affliction that can severely impair the lives of both the individual diagnosed with the illness and the individuals who act as caregivers (World Health Organization [WHO], 2012). The term dementia refers to a clinical syndrome that can encompass many types of cognitive impairments, the most common of which is memory loss (Barkhof, Fox, Bastos-Leite, & Scheltens, 2011). It consists of many subtypes including Alzheimer's disease, frontotemporal dementia and vascular dementia (WHO, 2012). The syndrome itself is typically progressive, beginning with a slight interference with activities of daily living in the early stages, and, eventually, a completely dependent end stage wherein all self-care ability is lost (Barkhof et al., 2011). As a result, this disorder can potentially place heavy burdens on the patients, caregivers, families and healthcare system (Barkhof et al., 2011). The onset of this syndrome typically occurs after the age of 65 and can have a duration ranging from 0.5 to 21 years with a mean duration of six years (Barkhof et al., 2011; Prasher & Krishnan, 1993). Moreover, as the baby boomer population is reaching this age threshold, it is imperative

that issues pertaining to dementia care become a priority for both researchers and policy-makers due to the potentially imminent increase in the prevalence of dementia (Krishnamoorthy, Prince, & Cummings, 2010).

The number of individuals afflicted with this illness worldwide, as of 2010, has been estimated to be 35.6 million and is projected to double by 2030, potentially reaching 115.4 million people by 2050 (The Alzheimer's Society of Canada, 2011; WHO, 2012). As the prevalence of this disease is increasing exponentially, it is understandable that it will have a substantial impact on the healthcare systems worldwide (WHO, 2010). Moreover, as the number individuals diagnosed with the disorder increase, so will the number of individuals who act as support for this population. Relevant literature divides this support network into two categories, namely, individuals who are a part of healthcare or support services (i.e., formal caregivers), and individuals who are family or friends (Peckham, Williams, & Neysmith, 2014). The first group is comprised of doctors, nurses, social workers, occupational therapists and personal support workers, while the latter includes wives, husbands, children, friends and neighbours (i.e., family caregivers or informal caregivers; Peckham et al. 2014). Unfortunately, the latter group often lacks support and acknowledgement for their efforts (WHO, 2012). For the purposes if this research project, focus was solely on familial caregivers.

Individuals who act as caregivers may take on this role in part due to emotional bonds, filial piety, or moral obligation (WHO, 2012). However as the disease progresses, the responsibility and burden begins to negatively affect the caregiver as well as their quality of life (Barkhof et al., 2011; Knight & Sayegh. 2010; WHO, 2012). This can result in caregivers developing mood disorders such as major depression (WHO, 2012).

As PwDs near the later stages of their illness, their ability to live independently becomes severely impaired and they become dependent on their caregiver to make decisions on their behalf (Bravo et al., 2013). These decisions include resolving financial matters as well as determining medical treatments (Bravo et al., 2013; Kaldjian, Shinkunas, Bern-Klug, & Schultz, 2010).

Caregivers may be asked to provide health care professionals proxy ratings of mood and quality of life. Caregivers are some of the few individuals that can provide insight on treatment efficacy and quality of life to healthcare professionals when disease progression impairs the communication abilities of the PwD. Therefore, it is imperative that researchers study any potential inaccuracies in communication on behalf of patients in the caregiver's proxy ratings. This is needed so that the health care team may seek to improve quality of life and adjust treatment for the PwD and to interpret research that relies on proxy ratings (Kaldjian et al., 2010).

A review of the literature has shown that caregivers may be inaccurate in providing proxy ratings regarding quality of life and mood (Kaldjian et al.,2010; Karlawish, Casarett, Klocinski, & Clark, 2001; Logsdon, McCurry, Moore, & Teri, 1997). Moreover, the literature suggests that caregiver burden may influence proxy ratings provided by caregivers (Rosenberg, Mielke, & Lyketsos, 2005). Caregivers have also been shown to exhibit depressive symptoms (Burke et al., 1998). Caregiver depression can potentially affect their ratings of PwDs (Rosenberg, Mielke, & Lyketsos, 2005). Furthermore, a review of the literature indicates that caregivers may exhibit more depressive symptoms than PwDs and caregiver burden may affect their proxy ratings of people with dementia (Burke et al., 1998; Rosenberg, Mielke, & Lyketsos, 2005).

Research Purpose

The researcher answered the guiding questions of this research project by analyzing an already accumulated data set. This data was acquired from an ongoing multi-site longitudinal study being conducted jointly by the University of Alberta, University of Ottawa and Brock University. The study utilized several measures that were administered to PwDs and their caregivers. Participants in this study were residents of Edmonton, Calgary or Ottawa.

The current project sought to contribute to the existing body literature regarding the measurement of quality of life of PwDs, as well as better understand factors that influence proxy ratings made by family caregivers on behalf of PwDs. This research utilized a Canadian sample from multiple cities adding to the knowledge base as well as contributing to clinical settings where health professionals rely on proxy ratings.

Chapter 2: Literature review

The following chapter contains four topics that will be covered in depth, namely: (1) background, which includes subtopics of dementia and caregiving; (2) theoretical models of caregiver burden, appraisal of burden, and potential impact on caregiver; (3) the utility of proxy ratings and caregiver efficacy of providing proxy ratings; and (4) summary of the literature on caregiver burden and proxy ratings. This chapter will conclude with proposed research questions.

Background

Dementia. Dementia is an umbrella term used to characterize an acquired neurological disorder with a similar collection of symptoms or cognitive impairments (Barkhof et al., 2011). It is usually characterized by impairments in, but not limited to, memory, language, movement, visual-perceptive, and executive function (e.g., decision making, attention, and problem solving; Barkhof et al., 2011). Though many of these changes are related to normal aging, it is when these issues are beyond age related degradations that they are considered symptomatic of dementia (Bartfay, Bartfay & Gorey, 2013). Various levels of clinical certainty can be reached regarding the diagnosis of dementia, however it can only truly verified post-mortem (Barkhof et al., 2011). Unfortunately, there is currently no cure for this collection of diseases nor is there a treatment to impede their progression (WHO, 2012).

Contrary to common belief, dementia is not exclusively an old person disorder. The disease can afflict younger individuals; as such dementia can be categorized as either young onset or late onset (Bakker et al., 2013). The differentiating criterion between the

categories is dependent on whether onset occurred before or after the age of 65 (Bakker et al., 2013; Barkhof et al., 2011; WHO, 2012). Young onset dementia is a rare condition and typically carries a greater burden for caregivers (Freyne, Kidd, Coen, & Lawlos, 1999). The increased burden is associated with disease-related caregiving responsibilities in addition to parenting responsibilities (Bakker et al., 2013; Freyne et al., 1999). For the purposes of this research project, the researcher examined data collected solely from late onset dementia patients and their caregivers.

The World Health Organization (2012) reported that dementia is the leading cause of disability and dependency among individuals aged 65 and older. It is also the primary cause of institutionalization among older adults; 20.0% of individuals diagnosed with dementia are institutionalized or move to a long-term care home within the first year and 50% after five years (Luppa et al., 2008). Motiwala, Croxford, Guerriere, & Coyte (2006) reported that the diagnosis of dementia was related to increased odds of dying in long term care and differentiated significantly from mortality occurring elsewhere. With the demand for long-term care beds already constrained and projected to raise it is understandable that there is a shift towards home and community based care (ASC, 2010).

PwDs and their families may attempt to remain together as long as possible, delaying or avoiding admission to a long-term care home in an attempt to avoid the costs of institutionalization and/or stay together as a family as long as possible due to familial bonds; unfortunately by doing so caregivers may incur opportunity costs (i.e., foregone wages due to increasing duties and time spent caregiving; Alzheimer Society of Canada [ASC], 2010). The World Health Organization (2012) predicted that the worldwide cost

of dementia as of 2010 was estimated to be $604 billion US dollars. Furthermore, the current cost of dementia care for Canadians is $15 billion and it is projected to increase to $153 billion within a generation (ASC, 2010). The burden, be it financial, emotional, or medical, seems to be shared by caregivers, health networks and society.

There are numerous types of dementia; the most common subtypes include dementia of the Alzheimer's type, vascular dementia, dementia with Lewy bodies, and frontotemporal dementia (WHO, 2012). The following sections will discuss these dementia types.

Dementia of the Alzheimer's type. Also known as Alzheimer's disease, this type of dementia is the most common form of dementia (Bartfay, Bartfay & Gorey, 2013). It is also the seventh leading cause of death in the United States and is projected to climb as the prevalence of the disease increases (Alzheimer's Association, 2010). Barkhof et al. (2011) notes the age standardized prevalence of Alzheimer's disease is 4.4%. The disease is characterized by non-functional tissue known as neurofibrillary tangles and plaques which are indicative of neural cell death which in turn is associated with increasing memory impairment, difficulty concentrating and impaired reasoning (Touhy, Jett, & Ebersole, 2013). Furthermore, the literature speaks to the notion that individuals with Alzheimer's disease have a genetic predisposition to the dementia (Barkhof et al., 2011, 2012; WHO, 2012).

Vascular dementia. This type of dementia shares risk factors with cerebrovascular disease such as hypertension, diabetes, older age, and cardiomyopathy (Perry, 2012). Like other dementias there is no gold standard of diagnosis other than post-

mortem autopsy (Barkhof et al., 2011, 2012; Perry, 2012).The age standardized

prevalence for vascular dementia is 1.6% (Barkhof et al., 2011, 2012). This particular

dementia is characterized by memory impairment and executive dysfunction attributed to

vascular disease in the brain (Perry, 2012).

Dementia with Lewy bodies. This type of dementia is considered the second

most prevalent dementia after Alzheimer's disease (Mckeith et al., 2004). Dementia with

Lewy bodies is characterized by cognitive impairment, executive dysfunction, psychosis,

and Parkinsonian-like symptoms (Al-Harrasi, Aravazhi, & Al-Sinawi, 2013; Barkhof et

al., 2011, 2012; Mckeithet al., 2004). Due to its symptomatic resemblance with

Alzheimer's disease and Parkinson's disease dementia, it is often misdiagnosed (Al-

Harrasi, Aravazhi, & Al-Sinawi, 2013; Byrne, 1992).

Frontotemporal dementia. Frontotemporal dementia is more likely than other

types of dementia to be young onset (Borronia et al., 2012).This neurodegenerative

disease accounts for 5 to 15% of all dementia (Bird et al., 2003). Frontotemporal

dementia is characterized by extreme impulsivity and inhibition which may in some cases

lead to inappropriate sexual or criminal behaviour (Wang, Shen, & Chen, 2012).

Moreover, persons with this particular dementia also tend to exhibit executive

dysfunction and language abnormalities (Wang, Shen, & Chen, 2012). These symptoms

can sometimes lead to a misdiagnosis of a personality and/or mood disorder (Wang,

Shen, & Chen, 2012).

The current research project used data that includes various dementia subtypes as

well as the ones listed above. Though there is a great deal of cost and strain caused by the

prevalence of dementia, it is the psychological and emotional toll that the syndrome takes

on caregivers that is alarming (WHO, 2012; Burke et al., 1998). The following section will explore the role of the caregiver and what impact the role takes on the individual's wellbeing.

Course of Dementia

Dementia is typically chronic and progressive in nature (WHO, 2012). The WHO (2012) notes it is important to acknowledge that symptoms and progression of dementia vary across individuals and dementia subtypes.

The difficulties experienced by PwDs as outlined by the WHO (2012), are due in part to the neurological underpinnings of the disease subtypes resulting in cognitive decline (Selbeak, Engedal, Benth, & Bergh, 2014). Cognitive impairment is a defining facet of dementia because individuals afflicted with one of the various subtypes of dementia will likely experience cognitive deterioration (Steinberg et al., 2008). This cognitive deterioration takes the form of numerous neuropsychiatric symptoms which are related to increased care costs, higher degree of caregiver burden and reduced patient autonomy resulting in institutionalization (Banerjee et al., 2003; Drame et al., 2011).

Neuropsychiatric symptoms in dementia can take the form of impaired recall, apathy, depression, delusions, hallucinations, anxiety, agitation, disinhibition, irritability, elation and/or aberrant motor behaviour (Selbaek, Engedal, & Bergh, 2013; Selbaek et al., 2014; Steinberg et al., 2008). Moreover, the neuropsychiatric symptoms of dementia vary across subtypes with regard to severity and onset (Tschanz et al., 2011; Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2010). Indeed, Wetzels et al., (2010)

reported a difference in the progression of irritability and disinhibition in Vascular Dementia and Alzheimer's disease.

Throughout the course of dementia the severity of certain neuropsychiatric symptoms, such as agitation and apathy, have been noted to increase (Selbeak et al., 2014; Tschanz et al., 2011; Wetzels et al., 2010). Furthermore, certain symptoms such as aphasia may only become prominent or even arise in the latter stages of the disease (Selbeak et al., 2014; Wetzels et al., 2010). Moreover, declines in affective symptoms have been observed in the literature (Selbeak et al., 2014; Selbeak et al., 2013; Tschanz et al). For example, Wetzels et al. (2010) noted that though depression initially displayed the highest persistence of recorded symptoms, severity and prevalence of depression decreased within the researchers' observed two year timeframe. Furthermore, with regard to Alzheimer's disease, though the number and severity of neuropsychiatric symptoms did increase, the course of symptoms were variable, episodic and showed slow decline in 30.0% to 58.0% of individuals who survived 5 to 7 years after onset (Tschanz et al., 2011). Thus, it is apparent that varying types of dementia may display differing progressions of the disease and symptomatic profiles while they do share the similarity of overall cognitive decline (Wetzels et al., 2010).

Symptoms of dementia are not static in nature as certain neuropsychiatric symptoms may remain worsen or lessen throughout the course of the disease (Selbeak et al., 2014). The WHO (2012) outlines three stages of dementia progression to elucidate the varying symptoms of dementia and their severity during the course of the illness, namely; early stage (first to second year), middle stage (second to fourth year) and late stage (fifth year and onwards). Moreover, the stages outlined by the WHO (2012) are

variable from person-to-person with certain stages progressing more rapidly in certain individuals with decreased independence, while others may experience the same stage at a hampered rate.

The early stage is characterized by forgetfulness, difficulty communicating, difficulty concentrating, becoming less active, increased hostility as well as losing interest in activities and hobbies (WHO, 2012). Unfortunately many of the aforementioned symptoms that appear in the earlier stages of dementia are often overlooked as it is mistakenly thought to be a part of normal aging (WHO, 2012). During the second or middle stage of dementia, symptoms begin to cause more apparent limitations in daily activities (WHO, 2012). This includes difficulty comprehending time and date, requiring assistance with personal care such as bathing and dressing, increasing memory loss with the inability to recall events and names, disinhibition, hallucinations, and wandering (WHO, 2012). Lastly, in late stage dementia the individual will become near completely dependent on caregivers and be generally inactive (WHO, 2012). The PwD will be unable to recognize friends and family, while requiring assistance with eating. Furthermore, individuals with dementia may potentially be unable to swallow, as well as have urinary and bowel incontinence (WHO, 2012).

Caregiving

Due to the growing prevalence of this illness, it is likely an increasing number of individuals will take on the caregiver role (WHO, 2012). Caregivers of PwDs often take on this responsibility because of affection towards that individual or a sense of filial obligation (WHO, 2012). Schulz and Martire (2004) note that while there is no

quintessential definition of familial caregiving, the authors acknowledge the following as a general consensus:

> The provision of extraordinary care, exceeding the bounds of what is normative of usual in family relationships. Caregiving typically involves a significant expenditure of time, energy, and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting. (p.1)

The literature differentiates between two distinct types of caregiving, formal and informal (Ku, Liu, & Wen, 2013; Goh, Lai, Lau, & Ahmad, 2013). Formal caregiving refers to individuals or services that are paid for; this includes doctors, nurses, and personal support workers (Goh et al., 2013). Informal caregiving involves services or care provided free of charge; people in this category include family, spouses, friends and neighbours (McMaughan-Moudouni, Ohsfeldt, Miller, & Phillips, 2012). Furthermore, it should be noted that these categories are not independent entities, rather these services work advantageously when utilized complementary to one another (McMaughan et al., 2012). For the current research project, the researcher focused on informal caregiving, specifically family caregivers. The following subsections will discuss family caregiving, the burden placed upon caregivers and caregiver depression.

Family caregiving. The role of the family caregiver is typically underappreciated and under supported (WHO, 2012). The majority of individuals diagnosed with dementia are taken care of by informal caregivers at some point during the progression of the disease (Quinn, Clare, McGuinness, & Woods, 2012). Though the role of family

caregiver is usually taken up by spouses and adult children, it can also include sibling in-laws, neighbours and friends (WHO, 2012). The primary caregiver is typically a family member who may co-habit with the PwD (WHO, 2012). Family caregivers of PwDs are also typically female (Pinquart & Sorensen, 2003).

The WHO (2012) notes that family caregivers play a multifaceted and vital role in caring for PwDs such as providing emotional support upon onset of diagnosis, providing assistance with personal finances and ensuring the PwD is reminded of events or tasks in the early stage of the disease. As the disease progresses, so too does the role of the family caregiver. During the middle stage of dementia family carers may be required to respond and ameliorate behavioural disturbances, assist with personal hygiene/care, as well as assist in other activities of daily living such as food preparation and dressing (WHO, 2012). Finally, in the late stage of dementia the family caregiver role becomes a round the clock endeavour providing full assistance with eating, drinking, bathing, mobilizing and toileting (WHO, 2012).

The burden that caregiving places on family members is substantial (WHO, 2012). Furthermore, this burden is not limited to stress and emotional wellbeing, but is a strain on resources as well such as money and time (Schulz & Martire, 2004). Family caregivers do not only view their responsibilities as a source of strain (WHO, 2012). Some individuals view the role as rewarding and provide them with a purpose (Wolff, Dy, Frick, & Kasper, 2007). A report surveyed a national representative population of Canada regarding caregiver views (World Alzheimer's Report, 2009). Of those who were surveyed, positive reasons for caregiving included companionship, fulfillment, and

enjoyment (World Alzheimer's Report, 2009; WHO, 2012). Though the role of a

caregiver may have many positive aspects, it is also fraught with hardship.

Caregiver Burden

A commonality across the literature regarding caregiving, is that taking upon the

role and responsibilities of a caregiver, in and of itself can cause an impact on the

individual (Quinn, Clare, & Woods, 2010). The current trend in the literature embraces

stress and coping models to explain individual outcomes and responses to the caregiving

"impact" (Knight & Sayegh, 2010; Quinn et al., 2012).

Caregiver burden can be dichotomized into two types of burden, each with

independent and distinct correlates, namely objective and subjective burden

(Montgomery, Gonyea, & Hooyman, 1985). Objective burden is defined as the activities

and events related to providing caregiving while subjective burden is the resultant

feelings and emotions (Montgomery, Gonyea, & Hooyman, 1985). Hoffmann & Mitchell

(1998) state that the subjective burden of a caregiver is characterized by fatigue and stress

due to negative appraisal of the caregiving scenario, which can in turn endanger the

physical and psychological health of the caregiver (as cited by del-Pino-Casado, Millán-

Cobo, Palomino-Moral, & Frías-Osuna, 2014).

Stress and coping models have been elaborated by several authors (for example,

Chun, Knight, & Youn, 2007; Kim, Knight, & Flynn, 2007; Sörensen & Pinquart, 2005).

These models derive from the stress process model created by Pearlin, Mullan, Semple

and Skaff (1990) which itself is an evolution of the Lazarus and Folkman (1984) theory

of stress, coping and adaptation (as cited by McCleary & Blain, 2013). They consider the

appraisal of burden and how it may affect caregiver's health (Knight & Sayegh, 2010). The pathway for this model is that behavioural problems of the person with dementia and other stressors contribute to the caregiver's appraisal of the stress of caregiving and, ultimately, the well-being of the caregiver (Knight & Sayegh, 2010). According to these stress and coping models of caregiver burden (Knight & Sayegh, 2010; McCleary & Blain, 2013), the behaviour, symptoms, loss of functioning of the PwD and the caregiving tasks are primary stressors for caregivers. Other stressors, called secondary stressors (e.g., work related) influence how the stress of caregiving is perceived and experienced. Caregiving stress is a process of appraisal of stressors, with appraisal influenced by factors within the caregiver (e.g., values, knowledge, self-efficacy), factors in the caregiving context (e.g., cohabitation with the PwD or kin relationship to the PwD), and factors in the environment (e.g., social support and services). Social support available to caregivers may decrease as the disease progresses; caregivers may also become socially isolated due to the demanding nature of their work, further compounding stress and strain associated with caregiving (WHO, 2012). Appraisal is also influenced by how the PwD copes with the stressor.

Caregivers develop coping strategies to mitigate the strain from caregiving. Caregiver resources and coping in turn influence caregiver outcomes (mood, quality of life, psychiatric morbidity, physical health). As dementia progresses, caregivers' responsibilities and caregiving duties increase and they experience increasing levels of stress (WHO, 2012). Furthermore, in the later stages of the disease, caregivers experience chronic fatigue and high levels of stress for longer periods as their caregiving responsibilities become more intensive (WHO, 2012). Family members of PwDs report

having lower general health and life satisfaction than the general population

(Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Salguero, Kohn,

Salguero, & Marotta, 1988). Furthermore, as caregivers allocate more time to the PwD, it

comes at the expense of their leisure and sometimes their own responsibilities

(Abdollahpour, Noroozian, Nedjat, & Majzadeh, 2012).

Due to the stress and isolation of acting as a primary caregiver, these individuals

are highly susceptible to depressed mood and to mood disorders such as major depressive

disorder (WHO, 2012). A review of the literature does show that caregivers display

higher rates of depression and anxiety than the general population (Schulz & Martire,

2004). Moreover, the presence of dementia in a family setting can potentially alter family

interactions and contribute to the development of psychiatric illness in family members

(Schulz & Martire, 2004; Salguero et al., 1988).

Caregivers and Proxy Ratings

The role of the caregiver is dynamic, as elucidated above. The PwD may

progressively lose the ability to communicate their needs and wishes, leaving the onus

upon caregivers to make decisions for them (WHO, 2012). Caregivers that act as

surrogate decision makers for patients with middle-to-late stage dementia play a pivotal

role in handling their finances, participation in research, and medical treatments (Bravo et

al., 2013; Kaldjian et al.,2010).

As persons with moderate-to-severe dementia may lack the insight to

communicate their needs and accurately complete necessary assessments, it falls on the

caregiver to provide medical professionals with proxy ratings (Trigg, Watts, Jones, &

Tod, 2011). A proxy rating is a communication of information, be it needs, barriers or symptoms, provided by a caregiver on behalf of the PWD to a healthcare professional or measure. Typically a patient's self-assessment is regarded as the gold standard for accruing patient information; however proxy ratings can act as a substitute (Arons, Krabbe, Scholzel-Dorenbos, van der Wilt & Rikkert, 2013). Arons et al. (2013), note that in addition to acting as a satisfactory substitution, proxy ratings used in addition to patient self-assessment can paint a greater picture of symptom presentation and quality of life. Furthermore, Bosboom, Alfonso, Eaton & Almeida (2012) related it may be beneficial to utilize self and proxy ratings in a complementary manner, rather than interchangeably, as both are driven by different factors and provide greater context of the patients wellbeing than using either independently. The validity and reliability of a proxy rating provided by a caregiver may help determine the therapeutic intervention necessary, evaluating current treatment, and in turn improve the quality of life of the PWD (Schulz et al., 2013).

Quality of Life Proxy Ratings

As the spectrum of dementia lacks any viable cure, quality of life has become recognized as an essential measure of assessing the clinical course and evaluating interventions (Crespo, de Quiros, Gomez, & Hornillos, 2012). As such, Schulz et al. (2013) related that bettering quality of life in PwDs should be a paramount concern. The term "quality of life" can be at times nebulous and difficult to come to an agreed upon definition, as Crespo et al. (2012) note. As quality of life is subjective in nature, many researchers utilize the WHO Quality of Life Group (1995) definition:

An individual's perception of their position in life in the context of the culture and

value systems in which they live and in relation to their goals, expectations,

standards and concerns. It is a broad ranging concept affected in a complex way

by the person's physical health, psychological state, personal beliefs, social

relationships and their relationship to salient features of their environment. (p. 1)

Therefore, the concept of quality of life is heavily subjective from person-to-

person and relies on the individual's own assessment. The current literature suggests that

PwDs with mild and moderate cognitive impairment are capable of making such

assessments of themselves, while those with moderate-to-severe dementia may have

difficulty with even the most straightforward assessments of quality of life (Crespo et al.,

2012; Sheehan et al, 2012). Crespo et al. (2012) note assessing quality of life implies the

individual has the cognitive capacity to make complex and insightful appraisal regarding

themselves and their respective lives. Furthermore, when assessing patients with

dementia on such a subjective concept, the complexity is further compounded as the

individual may lack insight into their condition (i.e., anosognosia) or have profound

impairment related to communication and understanding (Bruvik, Ulstein, Ranhoff, &

Engedal, 2012; Crespo et al., 2012; Schiffczyk et al., 2013).

Though reliable and valid proxy ratings provided by caregivers are tremendously

instrumental in ascertaining the wellbeing of PwDs, these ratings are not without

shortcomings (Arons et al., 2013). Namely, the current literature notes that there are

disparities among proxy ratings and patient ratings, with proxies underreporting quality

of life and over reporting psychological symptoms and burden (Arons et al., 2013; Crespo

et al., 2012; Sheehan et al., 2012; Novella et al., 2001). Sheehan et al. (2012) reported a

significant difference between patient ratings of quality of life and family caregiver proxy ratings, with the former typically rated as higher on both the EuroQOL (EQ-5D) and Quality of Life-AD (QOL-AD) assessments. Similar findings were noted by Crespo et al. (2012) in their research paper wherein proxy ratings of quality of life for persons with mild to moderate dementia were lower than patient ratings. The authors found the greatest concordance regarding observable indices of quality of life such as energy and decision making, while more subjective indices regarding family and overall life had the least agreement (Crespo et al., 2012). Novella et al. (2001) mirrored these findings in their report, with questionnaire type measures of quality of life having greater agreement than pictographic ones. This disparity between proxy ratings and patient self-assessment noted in the literature is dubbed as the "disability paradox" by Carr and Higginson (2001).

This disparity between proxy rating and patient self-assessment is not limited to dementia, it can be observed in other neurological disorders as well. Researchers have observed this phenomena occur in those with aphasia due to stroke (Ignatiou, Christaki, Chelas, Efstratiadou, & Hilari, 2012; Pickard et al., 2004). Ignatiou and colleagues (2012) reported the same discrepancy between proxy ratings and patient self-assessments regarding health-related quality of life, with proxies rating significantly lower than their counterparts. Pickard et al. (2004) also reported the presence of the disability paradox in their own research. Similar findings have been noted for family proxy ratings of quality of life of persons with schizophrenia (Becchi et al., 2004).

Moderating Variables of Proxy Ratings

Arons et al. (2013) conducted a study to observe whether caregivers of PwDs may project their own health related quality of life unto their proxy ratings of PwDs. The researchers utilized 175 dyads of caregivers and PwDs with mild-to-moderate dementia, who were assessed at three different time periods, at baseline, six months, and 12 months. Study participants were provided both the Quality of Life in Alzheimer's Disease (QOL-AD) and the EuroQOL five dimensions questionnaire (EQ-5D) to measure PwD quality of life. Arons et al. (2013) employed intra-class correlation coefficients to assess agreement between proxy and PwD ratings. The relationship between caregiver proxy rating and caregiver self-rating was investigated utilizing Pearson product-moment correlation coefficients. Lastly, the researchers utilized a linear mixed model regression approach assigning patient-by-proxy ratings of quality of life (utility score of the EQ-5D) as the criterion variable and caregiver age, sex, and caregiver self-ratings of quality of life at each time of the three time points were entered as predictor variables.

Arons et al. (2013) found Intraclass Correlation Coefficient (ICC) values of agreement on the EQ-5D VAS portion between patient-by-patient and patient-by-proxy ratings to range from slight-to-moderate at baseline (0.18), six months (0.22), and 12 months (0.42). ICC values ranging between 0.00 to 0.20 represent slight agreement, 0.21 to 0.40 represents fair agreement, 0.41 to 0.60 represents moderate agreement, 0.61 to 0.80 represents substantial agreement, and 0.81 to 1.00 represents almost perfect agreement (Arons et al., 2013). The ICC values for utility values/questionnaire portion of the EQ-5D were moderate at baseline (0.50), six months (0.46), and 12 months (0.51).

They noted significant correlations on EQ-5D VAS scores between proxy-by-proxy and patient-by-proxy ratings, ranging from weak-to-moderate strength at baseline ($r = 0.25$, $p = 0.001$), six months ($r = 0.43$, $p < 0.001$), and 12 months ($r = 0.25$, $p = 0.001$). The strength of correlation for this thesis were categorized in accordance with Dancey and Reidy (2004), that is correlation coefficients ranging from 0.1-0.3 are weak, 0.4-0.6 are moderate, 0.7-0.9 are strong and values of 0 and 1 represent strengths of zero and perfect respectively. Investigators interpreted significant correlations of proxy-by-proxy and PwD-by-proxy of quality of life as "projection bias", that is proxy raters projecting their on quality of life unto the PwD.

From the regression analysis, the variables noted to predict PwD-by-proxy scores were caregiver age, caregiver financial situation and caregiver valuation of life as a whole. Caregiver financial situation (money related item from proxy-by-proxy assessment of the QOL-AD) was found to contribute strongly ($p = 0.005$) to overall PwD-by-proxy VAS ratings. The negative association observed by researchers can be interpreted in the following manner, the higher the caregivers' financial status the more likely the proxy rater will provide poorer ratings on behalf of the PwD. Caregiver age was determined to also contribute to PwD-by-proxy VAS scores, where the higher the age of the caregiver the higher their rating of quality of life for the PwD. Lastly, how caregivers viewed their "life as a whole" also played a role on PwD-by-proxy VAS scores. The higher the caregiver's evaluation of "life as whole", the higher the PwD-by-proxy ratings.

Schulz et al. (2013) conducted a study to determine what factors were associated with family caregivers providing proxy ratings discrepant from those provided by the

PwD. Pairs of caregivers and PwDs ($n = 79$) completed quality of life instruments (QOL-AD and Dementia Quality of life Scale [Dem-QOL]) as well as a scales meant to assess suffering from psychological, existential, and physical perspectives. Caregivers provided proxy ratings on behalf of PwDs, while PwDs provided self-ratings. Moreover, PwDs were administered the Mini Mental State Exam (MMSE) to determine cognitive function. The individuals who scored lower than 16 on the MMSE were removed from the study, as the researchers deemed these PwDs would not be able to provide reliable responses. Of the sample, 79 dyads completed the baseline assessment and 54 dyads completed the follow-up a year later.

The researchers found weak-moderate correlations between PwD-by-proxy and PwD-by-PwD ratings of quality of life and measures of suffering, ranging from an r of 0.35 for the QOL-AD and 0.28 for the existential suffering scale. This weak-to-moderate correlation between ratings was consistent a year later upon follow-up ($r = 0.38$). The researchers also found statistically significant correlations ($p<0.01$) at baseline between PwD-by-proxy and PwD-by-PwD rating discrepancies of quality of life (QOL-AD and Dem-QOL) and the proxy-by-proxy scores on the Center for Epidemiologic Studies Depression Scale (CES-D), burden, as well as health status. These correlations ranged from an r of -0.40 for the QOL-AD rater discrepancy with caregiver burden, to 0.30 for the QOL-AD discrepancy with caregiver health status. Lower discrepancy between raters is representative of better agreement between them. Caregiver depression (CES-D) and burden were negatively correlated with quality of life discrepancy on both the QOL-AD and Dem-QOL, whereas caregiver health status was positively correlated to rater discrepancies on both measures (Schulz et al., 2013). Household income was found to

positively associated with rating discrepancy on the QOL-AD (Schulz et al., 2013).

Therefore, better caregiver health status and household income were associated with

better rating agreement whereas caregiver burden and depression were associated with

worse agreement between proxy and PwD raters.

Lastly, Schulz et al. (2013) conducted a multivariate regression to investigate

associations between individual predictors and caregiver patient discrepancies. The

outcomes of this analysis are poorly laid out and difficult to interpret. For this reason,

this particular analysis will not be utilized in the current literature review.

Vogel, Mortensen, Hasselbalch, Andersen, and Waldermar (2006) sought to

investigate whether quality of life differed between PwD-by-PwD and PwD-by-proxy

reports. The sample for the study consisted of 48 PwD at an early stage of the disease and

48 familial proxy raters of which the majority were spouses ($n = 28$). Proxy raters and

PwDs were provided with the EQ-5D and QOL-AD to measure quality of life. The

MMSE, Geriatric Depression scale, Danish Adult Reading Scale, Category Cued Recall,

Frontal Behavioural Inventory and an unnamed test of anosognosia were also provided to

PwDs. Agreement between raters on PwD quality of life was explored in addition to what

factors may be associated with it. Agreement was determined by way of intra-class

correlation between PWD and proxy ratings and t-test of differences, to which the

researchers found significant differences between the rating groups ($t = 2.6$, $df = 42$, $p =$

0.012) and poor Pearson's correlation between raters on both the EQ-5D VAS ($r = 0.33$)

and QOL-AD ($r = 0.33$; Vogel., 2006). Utilizing the anosognosia measure, Vogel et al.,

(2006) divided the PwDs into those with full insight ($n = 17$) and those with impaired

insight ($n = 29$). A significant correlation was noted between PwD-by-PwD and PwD-by-

proxy ratings for the full insight group on both the EQ-5D ($r = 0.61$, $p = 0.02$) and QOL-AD ($r = 0.52$, $p = 0.049$), but not for the impaired insight group. Therefore the presence of anosognosia may result in or further compound disagreement between raters. It is important to note that while the presence of anosognosia is common in dementia, it is not typical of someone with early stage dementia (WHO, 2012).

Conde-Sala, Garre-Olmo, Turro-Garriga, Lopez-Pousa, and Vilalta-Franch (2009) conducted a cross-sectional study to explore rating discrepancy and associated factors. The sample for the study consisted of 236 family caregiver-PwD dyads who were provided the QOL-AD, socio-demographic questionnaire and a clinical examination (Conde-Sala et al., 2009). The additional questionnaires consisted of Cambridge Cognitive Examination-Revised, MMSE, Disability Assessment for Dementia, and Neuropsychiatric Inventory (Conde-Sala et al., 2009). Caregivers were also provided with the SF-12 Health Survey and Caregiver Burden Index (Conde-Sala et al., 2009). Stage of dementia for PwDs was not reported by researchers. Caregiver relationships to PwDs were predominantly spousal (43.6%) or child (46.2%; Conde-Sala et al., 2009). Ratings on the QOL-AD for PwD-by-proxy and PwD-by-PwD were found to differ significantly ($z = -7.46$; p<0.001; d=0.63) with PwDs rating higher than their caregivers (Conde-Sala et al., 2009). The effect size was moderate-high (Cohen's $d = 0.62$). Moreover, when caregivers were grouped based on their relationship to the PwD, spousal caregivers were noted to rate quality of life higher for the PwD than an adult child caregiver (Conde-Sala et al., 2009). A significant difference was noted when comparing QOL-AD ratings provided by sons/daughters and spouses (Conde-Sala et al., 2009). This may indicate that spousal ratings may be closer to PwD rating than those provided by the children of PwD.

The authors followed this study by further exploring the impact caregiver relationship to PwD might have on proxy ratings of quality of life (Conde-Sala, Garre-Olmo, Turro-Garriga, & Vilalta-Franch, 2010). With a slightly larger sample of 251 dyads comprised of spouses (44.6%) and adult children (55.3%), the researchers found again that spousal caregivers were more positive of their PwD-by-proxy ratings of quality of life and displayed slightly better agreement with PwD-by-PwD ratings than adult children raters (Conde-Sala et al., 2010). A multivariate linear regression conducted by the researchers found relationship between the caregiver and the patient to be a significant predictor of PwD-by-proxy ($\beta = $-$0.19$, $p = 0.001$) and PwD-by-PwD ($\beta = $-$0.27$, $p<0.001$) ratings of quality of life. The authors also noted positive PwD-by-proxy ratings to be associated with higher educational level of caregiver ($\beta = 0.19$, $p<0.001$) and greater functional autonomy ($\beta = 0.35$, $p<0.001$), while poorer PwD-by-proxy ratings were associated with greater caregiver burden ($\beta = 0.23$, $p<0.001$), being an adult child caregiver ($\beta = $-$0.19$, $p = 0.015$), caregiver depressive symptoms ($\beta = $-$0.24$, $p<0.001$) and caregiver apathy ($\beta = $-$0.21$, $p<0.001$). Negative ratings of PwD-by-PwD were associated with having an adult child caregiver ($\beta = $-$0.27$, $p<0.001$) and depressive symptoms for PwD ($\beta = $-$0.32$, $p<0.001$).

Bosboom et al. (2012) conducted a study to observe agreement between PwD and proxy raters as well as explore what factors may be associated with quality of life ratings. A total of 80 caregiver-PwD dyads residing within a community were recruited for the study, with caregivers being family members and PwD presenting probable mild to moderate Alzheimer's disease (Bosboom et al., 2012). The primary outcome measure of

interest was the QOL-AD, which was completed by caregivers and PwD (Bosboom et al., 2012). The researchers reported acceptable agreement utilizing Bland-Altman plots. That is, agreement between PwD-by-PwD and PwD-by-proxy were within ±1.96 SD (Bosboom et al., 2012). While the authors of the study did not evaluate what factors may be associated with rater agreement, the researchers did note what factors were associated with PwD-by-PwD ratings and PwD-by-proxy ratings individually (Bosboom et al., 2012). The researchers conducted a univariate analysis and found PwD self-ratings of quality of life to be inversely associated with scores on the Hospital Anxiety and Depression Scale (HADS), Neuropsychiatric Inventory (NPI; Psychological and behavioural evaluation), and Guidelines for the Rating of Awareness Deficits (GRAD; Bosboom et al., 2012). That is, higher self-ratings of QOL were associated with lower reported PwD depression, fewer behavioural symptoms, and fewer awareness deficits. The PwD-by-proxy ratings were inversely associated with the HADS depression scores, NPI, Activities of Daily living and Instrumental Activities of Daily Living (Bosboom et al., 2012). The PwD-by-proxy ratings were also positively associated with cognitive scores of PwDs (Bosboom et al., 2012). That is, higher ratings by the proxy were associated with lower reported PwD depression, fewer behavioural symptoms, fewer difficulties engaging in instrumental activities, and better cognitive capacity. According to the authors, these findings suggest the factors associated with PwD-by-proxy ratings are not identical to those influencing PwD-by-PwD ratings and therefore may contribute to rating discrepancy.

Moyle, Murfield, Griffiths and Venturato (2012), conducted a similar study to Bosboom et al. (2012) seeking to explore agreement between proxy-PwD agreement and

factors associated with quality of life ratings. The sample for the study was comprised of 58 triads, namely PwDs residing in long-term care centres, family caregivers, and care staff (Moyle et al., 2012). The primary measure of quality of life was again the QOL-AD (Moyle et al., 2012). Agreement across all three raters was reportedly poor for consistency (association between raters' scores; ICC = 0.298; CI = 0.136-0.468) and absolute agreement (interchangeability of raters; ICC = 0.274; CI = 0.117-0.442; Moyle et al., 2012). Posthoc pairwise comparisons showed that the PwDs differed significantly from both family caregivers and staff. Conducting a multivariate analysis of variance (Pillai's Trace), the researchers noted PwD-by-caretaker ratings to be associated with Activities of Daily living scores (F [9,99] = 2.28, p = 0.02), with PwD-by-proxy/family caregiver exhibiting similar results but outside of statistical significance (F[3,33] = 2.53, p = 0.07; Moyle et al., 2012). This effect was not found in PwD-by-PwD ratings, suggesting factors that influence proxy rating may not exert the same effect on PwD ratings.

Zhao et al. (2012) conducted a study in which the researchers explored variables associated with the differences between PwD-by-proxy and PwD-by-PwD ratings. A total of 122 dyads were recruited with PwDs diagnosed with mild to moderate Alzheimer's Disease age 65 and older (mean age 82 ± 6 years). There was no requirement of familial relationship for caregivers but the caregiver sample was represented as 60.6% spouse and 39.4% "other" (Zhao et al., 2012). The authors utilized a cross-sectional design using the following measures: Quality of Life in Alzheimer's Disease (QOL-AD) Cornell Scale for Depression in Dementia (CSDD), Neuropsychiatric Inventory, a questionnaire requesting socio-demographic data, Zarit Burden Interview, MMSE, and the PAQUID modified

instrumental activities of daily living (iADL; Zhao et al., 2012). Researchers found ICCs between raters of between .02 and .59 for items and 0.58 for the overall score. Caregiver ratings were significantly lower than PwD ratings for the overall QOL-AD score and for 10 of the 13 items; they were significantly higher for the self-esteem item. By way of bivariate and multivariate analyses using a generalized linear model, Zhao et al. (2012) noted the difference between PwD-by-proxy and PwD-by-PwD ratings to be associated with PwD-by-PwD scores on the MMSE (cognitive function; $p = 0.02$), iADL, ($p = 0.02$), NPI ($p = 0.02$) and proxy-by-proxy score on the Zarit Burden Interview ($p = 0.02$). The researchers noted lower cognitive decline (higher MMSE scores, lower PwD functional ability, higher behavioural symptoms), and higher caregiver burden were all associated with greater discrepancy (Zhao et al., 2012).

Tay et al. (2014) followed a similar approach to inquiry to that of Zhao et al. (2012) seeking to understand PwD-proxy rating discrepancy regarding quality of life and factors associated with the discrepancy itself. Tay et al. (2014) recruited 165 community dwelling dyads of PwDs with mild-moderate dementia and caregivers consistently of mostly adult children (56.4%) and spouses (37%). Researchers utilized the QOL-AD as the measure of quality of life and the CSDD (PwD depression), Chinese MMSE, Bristol Activities of Daily Living Scale, NPI, Zarit Burden Interview, and socio-demographic data to determine what factors would be associated with rating discrepancy (Tay et al., 2014). The researchers reported ICCs for absolute agreement (ICC = 0.22 95% CI – 0.06 to 0.38) and consistency (ICC = 0.27, 95% CI = 0.12 to 0.14). Mean differences in scores were not presented. PwDs rated their quality of life higher than caregivers for most dyads (67.2%) (Tay et al., 2014). In a multiple regression analysis, controlling for patient and

caregiver age and gender the difference between PwD and caregiver rated quality of life was significantly predicted by patient educational level ($\beta = 0.76$, $p = 0.03$), PwD depressive symptoms (CSDD score; $\beta = -0.40$, $p < 0.01$), and behavioural symptoms (NPI score; $\beta = 0.67$, $p < 0.001$). Greater PwD education, higher symptom severity, and lower depressive symptoms were associated with greater rating discrepancy.

Gomez-Gallego, Gomez-Garcia, and Ato-Lozano (2015) conducted a study to explore rating disparity between PwD-by-PwD and PwD-by-proxy ratings in addition to factors associated with the discrepancy. A total of 138 dyads were recruited by researchers consisting of PwDs residing in community dwellings with family caregivers (Gomez-Gallego et al., 2015). The questionnaire provided to participants to assess PwD quality of life was the Dementia specific Health Related Quality of Life measure (DEMQOL; Gomez-Gallego et al., 2015). Participants were also administered the MMSE, Geriatric Depression Scale Short Form (SGDS), Neuropsychiatric Inventory (NPI), Clinical Insight Rating Scale (CIR), Zarit Burden Interview (ZBI), Health Utilities Index M3 (HUI3), and Cumulative Illness Rating Scale (CIRS; Gomez-Gallego et al., 2015). The authors conducted a cross-sectional analytic study observing rater difference as well as factors associated with individual difference and regression residuals (Gomez-Gallego et al., 2015). Significant difference was noted between PwD-by-PwD and PwD-by-proxy ratings on the DEMQOL ($p = 0.025$), with PwD typically rating higher than proxy raters (Gomez-Gallego et al., 2015). Gomez-Gallego et al., (2015) divided rating differences and regression residuals into positive and negative values. The researchers calculated individual difference scores by subtracting PwD-by-proxy score from the PwD-by-PwD score; positive differences indicated that PwDs rated higher and negative

differences that the proxy caregiver rated higher (Gomez-Gallego et al., 2015). Similarly, positive and negative residuals from the regression analysis were indicative of PwDs rating higher or caregivers rating higher, respectively (Gomez-Gallego et al., 2015). Multivariate analyses of predictors of differences are reported. For the overall DEMQOL score, positive differences were associated with caregiver burden and NPI mood; positive residuals were associated with caregiver burden. As such, greater rating differences wherein the PwD-by-PwD ratings were higher than PwD-by-proxy ratings were associated with greater caregiver burden and mood scores on the NPI. For the DEMQOL overall score, negative differences were associated with PwD pain; negative residuals were associated with PwD pain and PwD depression. For the DEMQOL feelings score, negative differences were associated with PwD pain and MMSE score; negative residuals were associated with PwD depression. Greater rating differences wherein the PwD-by-PwD ratings were lower than PwD-by-proxy ratings were associated with lower pain reported by PwD, PwD depression and cognitive impairment. Contrary to findings of Vogel et al., (2006), clinical insight was not associated with differences between PwD-by-proxy and PwD-by-PwD ratings of QOL.

In summation, across the studies reviewed, more studies found a significant difference reported between PwD-by-PwD ratings and PwD-by-proxy ratings of quality of life than otherwise. The tendency was for PwD-by-PwD ratings to be higher than PwD-by-proxy ratings. Three of four studies that examined predictors of differences between PwD-by-proxy and PwD-by-PwD ratings found that caregiver burden was associated with discrepancy. The fourth study (Tay et al., 2014) found that after controlling for the effects of age, gender, education, depression, and behaviour

symptoms, caregiver burden was not associated with discrepancy. One study found that other caregiver factors were associated with discrepancy, namely income, health status, and depression (Schulz et al., 2013). Three studies noted PwD factors were also associated with rating discrepancy (Gomez-Gallego et al., 2015; Tay et al., 2014; Zhao et al., 2012). Researchers of two studies that observed behavioural symptoms of PwD found them to be associated with rating discrepancy (Tay et al., 2014; Zhao et al., 2012). Two studies that observed PwD depressive symptoms reported it to be associated with rating disparity (Gomez-Gallego et al., 2015; Tay et al., 2014). The literature review found difference in scores between PwDs and caregivers was found to be associated with caregiver burden, caregiver age, caregiver socioeconomic status, caregiver quality of life, instrument activities of daily living of PwD, depressive symptoms of PwD, education of PwD, cognitive impairment of PwD, behavioural symptom severity of PwD, PwD pain, PwD mood, PwD psychosis, as well as relationship between caregiver and PwD.

Selecting Moderators

Moderator variable presence is typically indicated when a weak or inconsistent relationship is noted between predictor and criterion variables (Baron & Kenny, 1986). That is the relationship may hold or vary in strength depending on the subpopulation, setting or conditions (Baron & Kenny, 1986).

From the prior section, one can discern that many contributing factors can impact proxy rating agreement. Moreover, the literature has noted that agreement between proxy and patient rating vary from good to poor. Analogous to what Baron and Kenny (1986) noted, this range of rater discrepancy between patients and caregivers (i.e., inconsistent

relationship) may be indicative of certain factors moderating the relationship (or influencing the proxy's perception of the person with dementia). Few authors of published studies have viewed the impact of the mentioned variables from a moderation perspective; as such this novel avenue of inquiry may contribute to understanding of what influences caregiver proxy ratings.

The potential moderators and their relationship to proxy-patient rating agreement were not premeditated in their selection but emergent in the literature review that was conducted. Moreover, as this study utilized secondary data the study is constricted by the available data that were originally collected. In keeping with the review of the literature and the limitations of the present data, the moderator variables of interest for this project are caregiver depression, caregiver burden, caregiver quality of life, caregiver age, caregiver financial status, instrumental activities of daily living of PwD, education of PwD, cognitive impairment of PwD, behavioural symptom severity of PwD, PwD mood, as well as relationship between caregiver and PwD.

Due to the likely collinearity of caregiver depression, burden and quality of life only one of the three was selected for study, specifically caregiver burden due to its well documented impact on proxy ratings in the literature. Moreover, as caregiver burden and its impact on proxy rating bias has been observed in the literature, an analysis of moderation is a logical next step as a field of inquiry becomes more refined (Aguinis, Boik, & Pierce, 2001; Judd, McClelland, & Culhane, 1995 as cited by Frazier et al., 2004).

A moderator variable is defined as a variable that will reliably alter the relationship between predictor and criterion variables of interest (Sharma et al., 1981). Identifying moderators in a certain field speaks to the level of sophistication it has reached and the level of inquiry needed to make new strides in the literature (Aguinis et al, 2001; Judd et al., 1995 as cited by Frazier et al., 2004). Moderators typically uncover the conditions in which the strength and direction of the predictor-criterion relationship may vary (Frazier et al., 2004). Sharma et al. (1981) discern that moderator variables may be sorted into one of two categories. The first type affects the strength of the relationship between variables of interest and while second type of moderator variable modifies the form or type of relationship (Sharma et al., 1981). Kenny (2013) notes typically moderation implies the variable will weaken the predictive relationship; however a moderator variable can strengthen the relationship as well.

In summation, caregiver burden, caregiver age, caregiver financial status, instrument activities of daily living of PwD, education of PwD, cognitive impairment of PwD, behavioural symptom severity of PwD, PwD mood, as well as relationship between caregiver and PwD status are the potential moderator variables of interest.

Conclusion

There is a veritable cornucopia of published research regarding dementia and its various subtypes as well as caregiving for PwDs. It is apparent that dementia can diminish the PwD's ability to convey their quality of life or ability to adequately comprehend their symptom presentation and its impact on their daily life. Caregivers for PwDs have a great deal of responsibility that comes along with the role, which include

providing proxy ratings for PwDs regarding symptoms and quality of life when PwDs reach the stage where they are unable to speak to these issues themselves. The literature strongly suggests that there are factors that can influence proxy ratings of quality of life provided by caregivers on behalf of those with dementia or other neurological disorders. Indeed, the most prominently mentioned in the literature are a caregiver's burden, depressed mood, and quality of life. However, other potential contributing factors mentioned in the literature include caregiver age, caregiver financial status, instrumental activities of daily living of PwD, education of PwD, cognitive impairment of PwD, behavioural symptom severity of PwD, PwD mood, as well as relationship between caregiver and PwD. However, the field of proxy ratings and dementia caregivers is relatively novel and has few published manuscripts from which to make conclusions about the effects of caregiver burden and mood on proxy ratings. As such, the current research project is novel in that regard.

Research Questions

The purpose of the current thesis project is to examine the relationship between potential moderators and proxy ratings. The research questions for this research project are as follows:

(1) What is the level of agreement between proxy raters and PwD's self-ratings of quality of life?

(2) What factors moderate the relationship between proxy ratings and PwD ratings?

It was expected that there would be mild agreement between the PwD's self-rating of quality of life and caregiver proxy rating of quality of life, in line with the current

literature. Moreover, it is anticipated that caregiver depression, caregiver socioeconomic status, stage of dementia for PwD, caregiver gender, caregiver relationship to PwD, and PwD living situation would play distinct moderating roles on the proxy-patient rating relationship.

Chapter 3: Research Methods

This chapter will center on the description of research methods to be utilized for this project. The research methods to be employed will be explained while also describing the measurements and analysis that will be employed. Furthermore, potential channels of bias and how to address them will be described in this section.

Research Design

The thesis conducted a secondary analysis of existing data collected for a prospective longitudinal study with cross-sectional aspects. The authors of the original study that the data were drawn from are interested in exploring what roles environmental and personal factors have in predicting the outcomes of dementia related transitions. Moreover, the researchers sought to better understand what developments are needed in service configuration from the local to national levels to improve transitional outcomes. The primary study has received approval from two university research ethics boards, namely the University of Alberta Health Research Ethics Board and the Common Research Ethics Board of the University of Ottawa.

From the primary dataset this thesis utilized a total of $n = 107$ dyads of caregiver and PwDs. The researchers of the study employed a sample of administrative convenience. These individuals were recruited from geriatric clinics, memory clinics, local Alzheimer Societies, family practices, and dementia assessment units in Calgary, Ottawa, as well as Edmonton. Individuals with dementia were eligible for inclusion into the primary study if they were aged 65 or older, English or French speaking, received a diagnosis of dementia and were able to accurately recall past experiences prior to

diagnosis or had an informal caregiver who was able to do so in their stead. Furthermore, the individual must have been able to provide informed consent.

Data collection of the primary project consisted of four categories namely, initial and final "audits" of service provision, telephone calls to elucidate transitions, and cross-sectional data modules. Questionnaires were administered as part of cross-sectional data modules. These measures were distributed repeatedly from baseline and onwards at six month intervals until 30 months after initial recruitment. This thesis analyzed baseline data only. The instruments utilized for the study were included to target quality of life, mental health status, lifestyle and activities of daily living in caregivers and PwDs.

Secondary Data

Secondary data analysis has become a popular form of research analysis. With the advent of large information data bases as well as a plethora of efficient data collection methods, the utilization of secondary data has become an integral part of health data analysis (Reed, 1992). As this thesis utilized data collected for a larger project, it is essential that the method of secondary data analysis as well as its potential benefits and shortcomings be addressed.

Secondary analysis has been defined a multitude of ways, Glaser (1963) has defined this type of analysis as "existing data which was originally collected for other purposes" (p. 1, as cited by Reed, 1992). Though this definition is very broad it allows the encompassment of many secondary sources of data outside primary raw research data of another study, such as census data, reviews, and related health databases. Glass (1976) narrows this definition to the "re-analysis of data for the purpose of answering the

original research question with better statistical techniques, or answering new questions with old data" (as cited by McArt & McDouyl, 1985, p. 1). Our intent is to answer questions not pursued by the larger project by utilizing the old data. The definition this thesis will adhere to is the one set forth by Polit and Hungler (1983) wherein secondary data analysis is recognized as "a form of research in which the data collected by one researcher are reanalyzed by another investigator, usually to test new research hypotheses" (p. 261). Moreover, as secondary data analysis is employed for this thesis it is important to discuss the research modality's strengths and weaknesses.

Utilizing secondary data analysis can yield several benefits; here we will discuss those advantages relevant to the proposed thesis. McArt and McDouyl (1985) suggest classifying secondary data analysis strengths as scientific or functional. Some scientific advantages of secondary data include the potential to further enhance the primary data that was collected, develop new research foci and augment existing knowledge of the subject using existing data (McArt & McDouyl, 1985; Reed, 1992). Furthermore, investigators can reuse data while asking similar research questions while addressing it from a different theoretical perspectives, as well as answer new questions (McArt & McDouyl, 1985). A few functional benefits of secondary data are the efficiency and cost effectiveness of the methodology (McArt & McDouyl, 1985). As data collection, instrument development/compilation, and participant recruitment are typically time consuming and potentially costly, the exclusion of these steps using secondary data is greatly beneficial to the investigator (McArt & McDouyl, 1985).

Secondary data analysis is not without shortcomings, some of which will be discussed here. One such potential disadvantage is that the researcher who adopts

secondary data has little to no control regarding the selection, quality and methods employed in data collection as well as participant recruitment (Sørensen, Sabroe, & Olsen, 1996). This can make it difficult for the researcher to validate the techniques applied as the scope and resources employed in participant recruitment for the larger study are greater than that which can be employed by current researcher (Sørensen et al., 1996). However, this is not a limitation for the current research project. Furthermore, one of the most potentially harrowing drawbacks of secondary data is a poor fit between available data and research question (McArt & McDouyl, 1985). McArt and McDouyl (1985) note problems with the fit between data and research questions may fall into one of three categories namely; the unit of analysis, the definition of variables or the currency of the data. With these potential vulnerabilities, it is imperative that investigators using secondary data design research projects with the same rigour and attention to detail as those collecting primary data (Sørensen et al., 1996). Fortunately, the fit between data available, research questions, and gaps in the literature all coincide.

Instruments

This section will discuss the measures that were utilized for this thesis project. Measures that were employed in the primary study that will be analyzed for the current thesis project are the Caregiver Burden Inventory (CBI), Cornell Scale for Depression in Dementia (CSDD), Disability Assessment for Dementia (DAD), Functional Assessment Staging (FAST), Montreal Cognitive Assessment (MoCA), and Quality of Life in Alzheimer's Disease (QOL-AD). Instruments used to gather information regarding patients include the QOL-AD, DAD, CSDD, MoCA, and FAST. The measures employed to collect caregiver data include the EQ-5D, and CBI. The measure administered by

caregivers for proxy rating is the QOL-AD. The following section will elaborate on the

utility of each the previously mentioned measures as well as outline their reported

reliability and validity.

Table 3.1

Acronyms of Measures and Constructs Measured

Measure	Acronym	Construct
Quality of Life in Alzheimer's Disease	QOL-AD	Patient Quality of Life
Caregiver Burden Inventory	CBI	Caregiver Burden
Cornell Scale for Depression in Dementia	CSDD	Patient Depression
Disability Assessment for Dementia	DAD	Patient Disability
Functional Assessment Staging	FAST	Patient Stage of Dementia
Montreal Cognitive Assessment	MoCA	Patient Cognitive Status

Quality of life of person with dementia.

Quality of life – Alzheimer's disease (QOL-AD). The QOL-AD was first

developed by Logsdon, Gibbons, McCurry, and Teri (1999) to assess quality of life in

PwDs. The measure is viewed as a practical, yet efficient measure of quality of life due to

its brevity and psychometric properties (Akpinar & Kucukguclu, 2012; Thorgrimsen et

al., 2003). The QOL-AD has been translated and tested into numerous languages

including, French, Portuguese, Spanish, Japanese, Cantonese, Mandarin, and Korean

(Bowling et al., 2015). It is also regarded as the ideal measure of choice when evaluating

quality of life for psychosocial interventions (Moniz-Cook et al., 2008 as cited by Woods

et al., 2014).

The measure itself consists of 13 questions that maybe be completed either by a

PWD or a proxy rater (Wolak-Thierry et al., 2014). The items themselves cover various

facets of quality of life including physical health, energy, mood, living situation, memory, family, marriage, friends, the respondent as a whole ("you as a whole"), ability to do chores, ability to do things for fun, money and life as a whole (Logsden et al., 1999). These items are rated on a 4 point scale ranging from 1 (poor) to 4 (excellent) (Logsden et al., 1999). Total scores on the QOL-AD may range from 13 to 52, with a higher score indicating a higher quality of life (Wolak-Thierry et al., 2014).

The QOL-AD can be administered as to patients as an interview or to caregivers acting as proxy raters to complete independently (Akpinar & Kucukguclu, 2012). The questions created and incorporated into the measure by Logsden et al. (1999), were straightforward and coherent making the QOL-AD accessible to PWDs with a wide range of cognitive impairment/progression of dementia (as cited by Akpinar & Kucukguclu, 2012). The time for completion of the measure is 10-15 minutes for PWDs and around 5 minutes for caregivers (Akpinar & Kucukguclu, 2012).

The QOL-AD has been noted to be a psychometrically sound measure (Bowling et al., 2015; Thorgrimsen et al., 2003). The assessment has been stated to have good reliability; Wolak-Thierry et al. (2014) reported intraclass correlation coefficients for test-retest reliability over two weeks from 0.70 to 0.82. Thorgrimson et al. (2003) found similar results with intraclass correlation coefficients at 0.6 or higher. Cohen's kappa for test-retest was reported to be poor (<0.40) on a singular item while all other items displayed fair (0.40–0.59) or good (0.60–0.74; Thorgrimsen et al., 2003). Cohen's kappa for inter-rater reliability was good for the "memory" item and excellent for all other items (0.75-1.00; Thorgrimsen et al., 2003). Internal consistency of the measure was also good, with a reported Cronbach's alpha coefficient of 0.82 (Thorgrimsen et al., 2003). The

measure was also noted strong criterion validity (Thorgrimsen et al., 2003). Thorgrimsen et al. (2003) reported significant correlations with other measures of quality of life such as the Dementia Quality of Life, the EQ-5D questionnaire, and the EQ-5D visual analogue scale. As the focus of the project centers on proxy and self-report assessments of quality of life from this measure, the robust psychometric properties reported for the QOL-AD is reassuring.

Measures of potential moderator variables.

Cornell scale for depression in dementia (CSDD). The CSDD was initially developed to address an inherent problem in collecting self-reported depression data from PwDs utilizing existing measurement tools, namely that those with the affliction may have limited ability to adequately and accurately convey their own emotional state (Alexopoulos, Abrams, Young & Shamoian, 1988). The CSDD does not solely rely on the subjective patient self-appraisal, which could potentially be inadequate and unreliable, by shifting the focus to observable behavioural that is assessed by the clinician and caregiver (Kurlowicz, Evans, Strumpf, & Maislin, 2002)

The CSDD is a 19-item measure of depression administered to caregivers of PwDs so they may provide PwD-by-proxy (last week) rating of depressed symptom severity (Alexopoulos et al., 1988). The measure itself is typically utilized as a unidimensional tool (Kurlowicz, et al., 2002). Administration and rating of the CSDD is estimated to take approximately 30 minutes (Alexopoulos et al., 1988).

The measure is administered in two different portions, ideally by the same clinician to ensure a consistent and reliable interpretation of the data (Kurlowicz, et al., 2002). Firstly a clinician interview is provided to the patient's caregiver pertaining to

each of the 19-items (Alexopoulos et al., 1988). Following this the assessor will also

briefly interview the patient as well (Alexopoulos et al., 1988). In this portion of the

CSDD the interviewer is not confined to the questions provided and is encouraged to add

their own observations, inquiries, and probes (Alexopoulos et al., 1988).

The magnitude of each individual item in the CSDD is assessed and categorized

into the following three divisions: absent, mild/intermittent, or severe (Alexopoulos et al.,

1988). These divisions are represented with numerical values of zero, one and two

respectively (Kurlowicz, et al., 2002). Total summary score for the CSDD is expressed

numerically with a score ranging from 0-38 (Kurlowicz, et al., 2002). Conventionally a

score of 13 of higher is thought to be representative of major depression in PwDs

(Alexopoulos et al., 1988; Kurlowicz, et al., 2002).

The CSDD is scored based on the clinician's final judgement however, the

clinician is required to address and explain any discrepancy in caregiver's and clinician's

own observations (Alexopoulos et al., 1988). Should such a discrepancy arise between

the caregiver's account and the clinician's own report, it is the clinician's duty to

interview the caregiver once more to gain clarification before rendering a final judgement

(Kurlowicz, et al., 2002).

The CSDD has been noted to be a psychometrically sound measure (Alexopoulos

et al., 1988; Kurlowicz, et al., 2002; Vida et al., 1994). Alexopoulos et al. (1988) reported

good concurrent validity as significant correlations were noted between Research

Diagnostic Criteria (RDC) subtypes of depression (i.e., no diagnosis, episodic minor

depressive disorder, probable major depressive disorder, and definite major depressive

disorder) and the CSDD (Alexopoulos et al., 1988). This finding was later replicated in a

population of person's with probable mild to moderate Alzheimer's disease by Vida, Des Rosiers Carrier and Gauthier (1994).

The reliability of the CSDD was also noted to be good (Alexopoulos et al., 1988). The Cronbach's alpha reported by Alexopoulos et al (1988), suggested good internal consistency. Moreover, inter-rater reliability of the measure was noted to be substantial when the researchers employed a weighted Cohen's kappa coefficient (Alexopoulos et al., 1988). The measure was also noted to be sensitive, that is the instrument maintained a satisfactory true positive rate when discriminating major depression in PwDs (Alexopoulos et al., 1988; Vida et al., 1994).

Disability assessment for dementia (DAD). The DAD tool is used to measure capacity and ability of activities of daily living in individuals who may experience deterioration in this area due to cognitive decline (Gelinas & Gauthier, 1994).The DAD was initially conceived as a tool to objectively and accurately assess disability for community-PwDs (Gelinas & Gauthier, 1994). This instrument has been beneficial in informing clinicians' and caregivers' decisions regarding pursuing appropriate interventions and disease progression (Gelinas & Gauthier, 1994). Though initially constructed as a tool to be utilized with individuals with Alzheimer's disease, the measure is reported to be applicable to individuals with other dementia subtypes (Gelinas & Gauthier, 1994).

The DAD scale measures two major components of activities of daily living, namely functional disability and the cognitive dimensions of disability (Gelinas & Gauthier, 1994). The former is delineated into three areas of interest in the scale which comprises basic activities of daily living, instrumental activities of daily living and leisure

activities (Gelinas & Gauthier, 1994). The cognitive dimensions of disability in the measure include initiation, planning and organization as well as effective performance (Gelinas & Gauthier, 1994).

The DAD is administered to the caregiver of the PwD as an interview, with the caregiver providing proxy information about the PwD's functioning (Gelinas & Gauthier, 1994). This process takes approximately 15 minutes to complete, with the caregiver asked to relate experiences and information two weeks prior to the time of interview (Gelinas & Gauthier, 1994). Moreover, caregivers are asked to evaluate the patient's activities when they are unattended and not prodded, this is done to garner a better understanding of the patient's independent functional ability and cognitive capacity (Gelinas & Gauthier, 1994).

Questions for the instrument are answered with either a YES or NO, with any non-applicable questions removed from the final scoring process (Gelinas & Gauthier, 1994). Each YES will great a score of 1 and each NO a score of zero (Gelinas & Gauthier, 1994). With a total of 40 questions, a maximum score of 40 may be yielded (Gelinas & Gauthier, 1994). This score is then translated to a percentage (Gelinas & Gauthier, 1994). The lower the score on the DAD indicates fewer disability items exhibited by the PwD (Gelinas & Gauthier, 1994).

The measure is noted to robust in reliability and validity (Gelinas & Gauthier, 1994; Gelinas, Gauthier, McIntyre, & Gauthier, 1998). The DAD was reported to have good concurrent validity with the Rapid Disability Rating Scale-2 as well as severity of dementia in accordance with the Global Deterioration Scale (Gelinas & Gauthier, 1994). There is consensus in the literature that the DAD is a valid measure (Gelinas et al., 1998;

Feldman et al., 2001). Furthermore, Gelinas & Gauthier (1994) found the measure to exhibit reliability on test-retest, inter-rater and internal consistency. Similar findings of reliability were noted by Gelinas et al, (1998) as well as Feldman et al, (2001).

The Montreal cognitive assessment (MoCA). The MoCA was first developed by Nasreddine et al. (2005) to screen the presence of mild cognitive deficits in individuals who may be presented as having normal cognitive function in other measures (i.e., Mini Mental State Examination). The measure itself is a single page 30 point test that is meant to be administered in 10 minutes (Nasreddine et al., 2005).

These 30 items can be categorized into various cognitive faculties namely, visuospatial abilities, attention, concentration, executive functions, short-term memory, language, working memory, as well as temporal and spatial orientation (Freitas, Simoes, Maroco, Alves, & Santana, 2012). The tasks presented to individuals who undergo the MoCA include recall tasks, learning trials, a clock drawing task, a three dimensional cube copy, sustained attention task, digits forward and backwards task, among others (Nasreddine et al., 2005).

The literature has attested to the good psychometric properties of the MoCA (Freitas et al., 2012a; Freitas, Simões, Alves, Vicente, & Santana, 2012b, Freitas, Simões, Alves, Duro, & Santana, 2012c, Freitas, Simões, Alves, & Santana, 2013; Nasreddine et al., 2005). The measure has been noted to have good specificity and sensitivity in detecting mild cognitive impairment in individuals with Alzheimer's disease (Nasreddine et al., 2005). The MoCA was also noted to have good internal consistency, with researchers Freitas et al, (2012a) reporting a Cronbach's alpha of 0.90.

Researchers stated the tool exhibited excellent test-retest reliability and inter-rater reliability while also displaying good convergent validity in a population of individuals with Alzheimer's disease (Freitas et al., 2013). Similar psychometric robustness was been noted in populations with frontotemporal dementia and vascular dementia (Freitas et al., 2012b; Freitas et al., 2012c). In both populations researchers noted good internal consistency, as evidenced by way of excellent Cronbach's alphas, and the MoCA was also found to have good inter-rater reliability when used with individuals with frontotemporal dementia (Freitas et al., 2012b; Freitas et al., 2012c). Finally, the MoCA was noted to have good construct validity and display convergent validity with the MMSE in both the vascular and frontotemporal dementia populations (Freitas et al., 2012b; Freitas et al., 2012c).

Caregiver burden inventory (CBI). The CBI was initially developed by Novak and Guest (1989, as cited by Chou, Jian-Chyun, & Chu, 2002). The measure was initially created to assess the impact of burden on varying aspects of a caregiver's life (Chou et al., 2002; Marvadi et al., 2005). Marvadi et al. (2005) note, it is greatly beneficial that the CBI quantifies not only global burden like other modalities of burden assessment, but a variety of burden dimensions. This measure observed five different areas of dimension namely, time-dependent burden, developmental burden, physical burden, social burden, and emotional burden (Marvadi et al., 2005).

The CBI consists of 24 items with each item ranging from 0 (not at all descriptive) to 4 (very descriptive; Chou et al., 2002). A respondent completing the CBI can score a total ranging from 0 to 96 with a higher score representing a heightened

experience of burden (Chou et al., 2002). Administering the measure typically takes approximately 10 to 15 minutes (Chou et al., 2002).

Chou et al. (2002) state that many items of the CBI have been incorporated from other scales, which may in turn suggest some content validity for the measure. Moreover, an exploratory factor analysis of CBI items suggest there are five interpretable factors namely, time-dependent burden, developmental burden, physical burden, social burden and emotional burden (Chou et al., 2002). These factors were determined to account for 66% of variance and have Cronbach's alpha values of 0.85, 0.85, 0.86, 0.73, and 0.77, respectively (Chou, Jian-Chyun, & Chu, 2002). Marvardi et al. (2005) reported CBI internal consistency (Cronbach's alpha greater than 0.80). With the measure displaying sound psychometric properties and a multifaceted approach to burden appraisal, utilizing this tool will greatly assist in the collection of burden information. No tests of test-retest, convergent/divergent validity or criterion validity have been conducted on the CBI according to Chou, Jian-Chyun, and Chu, (2002), the literature review for this thesis proposal was also unable to locate these tests of psychometric properties.

Functional Assessment Staging (FAST). The FAST assessment tool was initially developed to assess changes of functional capabilities and staging in PwDs (Scalan & Reisberg, 1992). Though the measure was initially developed for individuals with Alzheimer's disease, it has been utilized with success on other forms of dementia (Scalan & Reisberg, 1992).

The scale consists of seven stages (1 to 7) which can further be delineated into eleven sub stages (Scalan & Reisberg, 1992). These substages are confined to the sixth and seventh main stages outlined by the scale and are itemized alphabetically (i.e., a

through e; Scalan & Reisberg, 1992). In total there are 16 FAST stages that a respondent

may be categorized into (Scalan & Reisberg, 1992). The functional stages attributed to

PwDs range from "Normal Adult" to "Severe Alzheimer's Disease" (Scalan & Reisberg,

1992).

The individual administering the FAST must observe and detect shortcomings in

complex daily tasks, choosing attire, self-care, incontinence among other lapses in

activities of daily living (for the full list of functional deficits and their complementary

FAST stage please see Appendix A; Scalan & Reisberg, 1992). Na et al. (2010) note

there may be several advantages to utilizing the FAST measurement tool, such as a larger

range of functional disabilities that can be placed on a spectrum of normal aging to severe

dementia, information may be obtained from a third party retrospectively if need be, and

measures can significantly contribute to a differential diagnosis of dementia.

The measure has been found to have good reliability and validity while

demonstrating great indication of functional decrement (Na et al., 2010). Scalan &

Reisberg (1992) determined the FAST to have significant intraclass correlation

coefficient by way of rater agreement and excellent reliability. These researchers also

noted the FAST exhibited exceptional concurrent validity with the MMSE and Ordinal

Scales of Psychological Development (Scalan & Reisberg, 1992). Na et al (2010) also

noted the measure displayed good inter-rater and test-retest reliability.

Data Cleaning and Missingness

The data collected and utilized in this project was subject to high rigour to ensure

the outcomes that may be extracted from them are accurate. As such it is important the

data be subject to meticulous data cleaning and steps taken to address missing data. The process of data checking and assessment is important, even for secondary data analysis.

Data quality control takes place at many stages throughout the research process (Pomerantseva & Ilicheva, 2011). Pomerantseva and Ilicheva (2011) suggest adhering to a set of data entry guidelines that had been outlined to prior to data collection; this includes premeditated handling of data anomalies/discrepancies, utilizing planned abbreviations and an accepted practice of data entry. Moreover to identify potential data errors, frequency tables with cross comparison of particular parameters were utilized (Pomerantseva & Ilicheva, 2011). The data anomalies rooted out were codes not possible given questionnaire/inputting restrictions (wild codes), unlikely occurrences, and outliers. Outliers in the dataset were identified and appropriately removed to prevent the data anomaly from skewing potential findings (Pomerantseva & Ilicheva, 2011).This was done as certain forms of analysis such as regression require outliers to be addressed. The identification of outliers was conducted by way of manual inspection and graphical presentation of data (Pomerantseva & Ilicheva, 2011).

Several steps were planned for data missingness at the proposal stage of the thesis, however as the dataset utilized was not missing any data the previously planned steps were not employed.

Data Analysis

The research questions presented in this project were addressed utilizing quantitative approaches. The techniques to be employed will be addressed in the following section and will include basic descriptive statistics, bivariate analyses as well as multivariate analyses.

Sample Description. Descriptive techniques were applied in order to adequately describe the sample and the variables. Demographic or sample descriptive variables that are categorical in nature were subject to frequency distributions. Mean, median as well as range were determined for continuous variables. Item values for each measure employed in this project also underwent similar descriptive techniques such as mean, median, range and standard deviation.

Testing internal consistency. Cronbach's alpha was computed for items in all measures with available item level data. This was computed for full scales only. For other measures (i.e., FAST), item level data are not available to compute Cronbach's alpha. Cronbach's alpha is a measure of internal consistency reliability of items on a scale. It can range from 0.00 to 1.00. Higher values of Cronbach's alpha are indicative of greater internal consistency (Polit, Lake, & Polit, 2010).

Testing agreement of QOL-AD. The first research question is: What is the level of agreement between proxy raters and raters with PwD regarding PwD quality of life? To answer this question, ICC was computed for the QOL-AD total score.

Testing moderation. The second research question is: What factors moderate the predictive relationship between proxy ratings and PwD ratings? Moderation was tested using regression analysis.

The analyses test whether the relationship between PwD quality of life as rated by the caregiver-proxy and the PwD is moderated by caregiver burden, caregiver depressed mood, caregiver quality of life, caregiver financial situation, PwD stage/duration of disease, PwD disability/cognitive impairment, caregiver gender, or caregiver-PwD relationship/living situation. These variables can potentially influence the caregiver-proxy

informant's perception of the PwD quality of life (and, thus, the relationship between proxy and PwD self-ratings; Kenny, 2013).

A moderator can be qualitative (categorical) or quantitative (continuous) variable that can affect direction and/or strength of the relationship between predictor and criterion variables (Baron & Kenny, 1986). In this study, the predictor variable is the PwD self-rated QOL-AD and the criterion variable is the caregiver-proxy rating of the PwD's QOL-AD. The selection of criterion and predictor variables were done in this manner as the predictor has influence upon the criterion, similarly the PwD self-ratings of quality of life affect the proxy rating however the proxy rating does not affect the PwD self-rating of quality of life. Baron and Kenny (1986) show three pathways that contribute to the criterion or outcome variable (Figure 1). This figure is adapted to show how moderation may be present in the thesis data. Pathway *a* is the association of the predictor variable with the outcome variable, in this case, how the PwD QOL associated with the caregiver's perception of that QOL. Pathway *b* is the impact of the moderator variable (e.g.., gender) on the caregiver's perception of PwD QOL. Pathway *c* is the interaction effect between the predictor variable and the moderator and its impact on the outcome variable (Baron & Kenny, 1986). A statistically significant interaction effect is evidence for moderation (Baron & Kenny, 1986). The main effects (pathways *a* and *b)* are not relevant to testing a moderator hypothesis (Baron & Kenny, 1986).
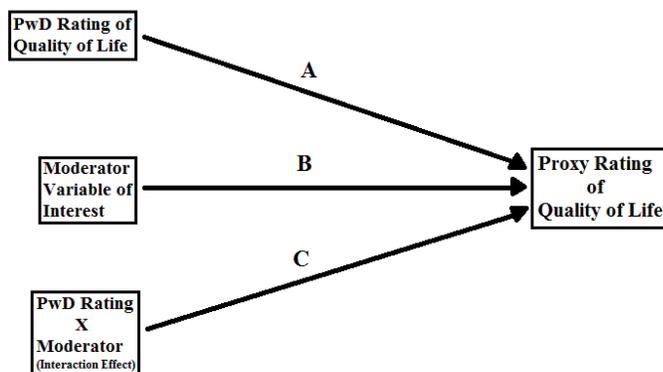
Figure 3.1. Moderator model pathways (adapted from Baron & Kenny, 1986).

Procedures for testing moderation described by Jose (2013) were used. These procedures are consistent with Baron and Kenny (1986). Jose (2013) provides more details.

Statistical assumptions of regression analysis were also tested. A regression analysis is statistical technique meant to analyse relationships and predict values of variables (Polit et al., 2010). For this project, multiple linear regression models were be computed to understand the impact of the selected moderated variables on proxy-patient ratings of quality of life. Moreover, a regression analysis is conducted to identify a line of best fit within a linear relationship with imperfect correlation (Polit et al., 2010). The line of best fit is determined utilizing a statistical criterion called least squares (Polit et al., 2010). This criterion is used to estimate parameters in a regression model, minimizing the sum of squared error terms (Polit et al., 2010). A linear regression was conducted for each moderator variable of interest. Multiple linear regression models were computed. Frazier et al. (2004), in their review of moderator and mediator effects, state that multiple regression analysis is the preferred statistical method.   Separate analyses were conducted for each moderator variable of interest.

Assumptions made by the moderator model are akin to those made by the ordinary least squares design of regression, namely that there will be no missing variables and an accurate outline of the model's functional form (Fairchild & Mackinnon, 2009). Moreover, moderation models also assume homogeneous variance of error (Fairchild & Mackinnon, 2009).

The regression equation for tests of moderation consists of three predictor terms; two main effects and one interaction effect (Jose, 2013). The following regression equation was utilized:

$$Y = i + aX + bM + cXM + E$$

Where Y represents the criterion variable or proxy rating, X represents the predictor variable or PwD rating, M is the moderator variable, XM is the interaction effect, i is the intercept, E is error and a through c are regression coefficients.

Frazier et al. (2004) advise centering the predictor as well as moderator variables when measuring on a continuous scale. As this project consisted of continuous moderators and predictor variables, it is important to consider this step in data analysis. Centering variables consists of placing them into deviation units by subtracting the sample mean from each variable value which will in turn create sample means of zero. The authors state this is done to reduce issues related to high correlation between moderators/predictors variables and the interaction term (Frazier et al., 2004). This high correlation between variables is known as multicolinearity (Frazier et al., 2004).

Paul E. Jose, in his book Doing Statistical Mediation and Moderation (2013), challenges this school of thought and states that centering data to reduce multicollinearity has "passed from 'helpful suggestion' to 'received wisdom'" (p. 158). He asserts that this

is no longer a necessary step in moderator research, citing research conducted by

Kromrey and Foster-Johnson (1998) which demonstrated that centering was, in fact,

superfluous and did not influence multicolinearity. Moreover, centering or lack thereof

did not change the moderation result (Jose, 2013). As such, Jose (2013) advises against

centering unless one wishes to create a figure wherein the moderator and predictor means

are zero. For the purposes of this research, data centering was not employed.

   Categorical moderators. In this study, the potential moderators of caregiver

income, PwD education, PwD behavioural symptoms and "relationship between

caregiver and PwD" were categorical variables. Baron and Kenny (1986), note the

conventional method of measuring moderator effects between continuous predictor

variables and dichotomous moderators is to correlate predictor and criterion variables

individually for each gender and test the difference of the correlation coefficients.

However, Baron and Kenny (1986) delineate two shortcomings with this method.

   The first concern is known as the restriction of range problem. This approach

assumes equal variance between differing levels of moderators (i.e., male and female;

Polit, Baron & Kenny, 1986). Should variances of the predictor and criterion variable

differ across categories of the moderator, correlations within the categories will be

affected (Baron & Kenny, 1986). The smaller the range of scores, the weaker the

correlation will be. The second problem put forth by Baron and Kenny (1986) is the

possibility that the amount of measurement error in the criterion variable may vary as a

function of the moderator. This in turn could lead to false correlations between predictor

and criterion variables (i.e., PwD and proxy ratings respectively; Baron and Kenny,

1986). Due to these potential errors, Baron and Kenny (1986) advise utilizing linear

regression analysis as regression coefficients (unstandardized) will not fall prey to these problems.

Dummy coding was used for categorical moderator variables of caregiver income, PwD education, PwD behavioural symptoms and "relationship between caregiver and PwD" as recommended by Frazier et al. (2004), Schroeder, Sjoquist and Stephan (1986) and Jose (2013). Dummy coding is usually employed to change multilevel categorical variables into ones that can be successfully employed in regression and correlation analyses (Jose, 2013). Arbitrarily assigning numerical values to category levels is insufficient; instead information contained within these variables should be translated into several dummy codes for meaningful analysis (Jose, 2013).

Typically the number of dummy coded variables used is one less than the total number levels for a categorical variable (e.g., if observing the moderating role of income brackets and there are total of four brackets of interest, there would be a total of three dummy coded variables; Jose, 2013). It is imperative when dummy coding to select a reference group (Jose, 2013). Group being compared to the reference group was assigned a value of one, while the remaining categorical levels were provided a value of zero (Jose, 2013). Dummy code one (Dum1) would compare a categorical level to the reference category, Dum2 would do the same for another categorical level, and so on until every categorical level of the moderator was assigned a dummy code except for the reference level (Jose, 2013). These coded dummy variables can now be utilized in multiple forms of analysis including multiple regression (Jose, 2013).

As recommended, following the coding of dummy variables, the product of the dummy code and predictor variable were calculated, thus creating an interaction term for

each dummy code for moderator variable (Jose, 2013). For example, if there are five levels for a categorical moderator variable (e.g. caregiver occupation), four dummy codes were created. The regression analysis for this example utilized the predictor variable, the four dummy codes, and four interaction terms (Jose, 2013).

Categorical hypothesized moderators were dummy coded, reference levels were selected based on the subcategory with the largest sample. The categorical variable relationship for analysis had spouse as the reference level. The reference level for education of caregivers was elementary education and secondary education combined due to small representative samples. Reference level for FAST staging was FAST 2 and FAST 3 combined due to small cell sizes. FAST levels of 1, 6c, 6e, and 7a through e were not reported and therefore analysis of these stages could not be completed..

Other avenues of analysis were considered for this project such as the Actor-Partner Interdependence Model (APIM) and observing differences in regression residuals. While the APIM does incorporate moderation and speaks to the interdependence of interpersonal relationships, thus providing a potentially comprehensive picture of the caregiver-patient rating dynamic, the current study lacks the necessary data to adequately employ this model (Cook & Kenny, 2005). Moreover, employing an analysis of regression residuals was considered but ultimately abandoned as the technique was seldom mentioned in moderation research and therefore likely less relevant for the purposes of this project.

Chapter 4: Results

The current chapter will present a description of the sample and findings from analyses that were conducted to address the proposed research questions. This section will delve into descriptions of demographic variables, participant responses to relevant measures, agreement between PwD and Caregiver proxy ratings of quality of life, and finally the results of multiple regression analyses to explore which hypothesized variables may play a role in the PwD-proxy rating relationship. It is important to note, though several steps were planned in case of missing data, all cases utilized for this project had complete data and therefore did not require the contingencies planned.

Sample Description

The secondary data utilized for this project consisted of 107 dyads of PwD and their caregivers. Table 4.1 delineates the frequency of categorical variables descriptive of this sample and relevant to the current thesis project. Of the PwD in the sample, 59 were female (55%) and the majority of caregivers were female as well ($n = 74$, 69 %). Majority of PwD in the sample had completed secondary level education (high school; $n = 47$, 44%) while the majority of caregivers had completed post-secondary level education (University/College; $n = 61$, 57%). Both the PwD and caregivers predominantly reported place of residence was their own home rather than assisted/supportive living, with 91 PwDs (85%) and 103 caregivers (96%) residing at home. Moreover, caregivers of this sample typically lived with the PwD with 75 (70%) individuals acting as live-in caregivers. Individuals acting as caregivers were predominantly spouses and children. From the total sample 54 individuals (51%) reported a spousal relationship to the PwD

and 42 (30%) were reportedly children of the PwD. A total of 101 individuals (94%)

were English speaking while the remaining participants were French speaking.

Caregiver socioeconomic status is one of the moderator variables of interest for this

project. To assess socioeconomic status while lacking self-reported income of

participants, I utilized caregiver education as it is also a measure of caregiver status.

Table 4.1

Sample Description: Categorical Demographic Variables of PwD and Caregivers

Categorical Descriptive	Categorical Sublevels	Sample ($n = 107$) n (%)
PwD Gender	Female	59 (55.1)
	Male	48 (44.9)
Caregiver Gender	Female	74 (69.2)
	Male	33 (30.8)
PwD Education	Elementary	17 (15.9)
	Secondary	47 (43.9)
	Post-Secondary	43 (40.2)
Caregiver Education	Elementary	3 (2.8)
	Secondary	43 (40.2)
	Post-Secondary	61 (57.0)
PwD Residence	Own Home	91 (85.0)
	Assisted/Supportive Living	16 (15.0)
Caregiver Residence	Own Home	103 (96.3)
	Assisted/Supportive Living	4 (3.7)
Caregiver's Living Arrangement	Live-In	75 (70.1)
	Live-Out	32 (29.9)
Caregiver Relationship to PwD	Spouse	54 (50.5)
	Sibling	4 (3.7)
	Child	42 (39.3)
	Friend	1 (0.9)
	Other	6 (5.6)
PwD Language	English Speaking	101 (94.4)
	French Speaking	6 (5.6)

Note. PwD = Person with Dementia

The frequencies of continuous variables are described in Table 4.2. The average age of the PwD ($M = 79.9$, $SD = 6.4$) was typically higher than that of the caregiver ($M = 63.3$, $SD = 15.6$). The average time passed since diagnosis of PwD who enrolled in the study was one year ($M = 1.0$, $SD = 0.5$).

Table 4.2

Sample Description: Continuous Demographic Variables of PwD and Caregivers

Continuous Descriptive	Mean	Median	Standard Deviation	Range	Minimum Value	Maximum Value
PwD Age ($n = 107$)	79.9	80.0	6.4	34.0	64.0	98.0
Caregiver Age ($n = 107$)	63.3	65.0	15.6	64.0	30.0	94.0
Time Passed since Diagnosis (Years; $n = 106$)	1.0	0.5	1.1	4.0	0.0	5.0

Descriptive Statistics and Correlations among Patient Quality of Life, Proxy Rated Quality of Life, and Hypothesized Moderators

As stated earlier in this project, there are five measures that were employed for the purposes of this study, namely the QOL-AD, DAD, CBI, CSDD and MoCA (To see all tests and their relevant information see Table 3.1). Table 4.3 delineates the descriptive statistics of each measure as well as their respective Cronbach's alpha (α). On average PwD rated their quality of life ($M = 38.9$, $SD = 5.3$) higher on the QOL-AD, than the rating provided by caregivers ($M = 34.3$, $SD = 6.7$). A paired t-test found significant effect, ($t[106] = -7.20$, $p < 0.001$), for the difference between proxy and PwD QOL-AD scores with PwD scoring their own quality of life higher than that provided by proxy

ratings. The mean percentage score for the DAD was 77% (SD = 20.1), that is typically

PwDs were able to complete 77% of the activities/items on the measure without help or

reminder in the two weeks prior to test administration. Caregivers' mean reported score

on the CBI was 19.8 (SD = 14.9), and PwDs' mean score for the CSDD was 3.9 (SD =

4.8). Respondent mean score for the MoCA was 17.1 (SD = 5.9). The five measures

utilized for this project displayed good reliability. The Cronbach's alphas calculated for

each measure ranged from 0.84 for the MoCA to 0.92 for the CBI.

Table 4.3

Measures Description: Participant Responses to Assessment Tools

Measure (*n* =107)	Mean	Median	Standard Deviation	Range	Minimum Value	Maximum Value	Cronbach's Alpha (α)
QOL-AD (PwD)	38.9	39.0	5.3	28.0	24.0	52.0	0.85
QOL-AD (Caregiver)	34.3	34.0	6.7	31.0	19.0	50.0	0.87
DAD	76.8	79.5	20.1	93.0	8.0	100.0	0.90
CBI	19.8	19.0	14.9	68.0	0.0	68.0	0.92
CSDD (PwD)	3.9	2.0	4.8	21.0	0.0	21.0	0.85
MoCA	17.1	18.0	5.9	28.0	2.0	30.0	0.84

Frequency of FAST scores, dementia staging and related behavioural symptoms

are listed in Table 4.4. The majority of PwDs who completed the FAST fell into the

fourth stage of dementia (*n* = 79, 74%) characterized by "Decreased ability to perform

complex tasks (e.g., planning dinner for guests), handling personal finances (forgetting to

pay bills), difficulty marketing, etc." (Reisberg, 1984).

A series of Pearson correlations were also conducted in order to exhibit the relationships between continuous moderatorss of interest and ratings of quality of life by both proxy raters and PwD (see Table 4.5). The strength of correlation for this thesis were categorized in accordance with Dancey and Reidy (2004), that is correlation coefficients ranging from 0.1-0.3 are weak, 0.4-0.6 are moderate, 0.7-0.9 are strong and values of 0 and 1 represent strengths of zero and perfect respectively. The correlation between PwD self-ratings of quality of life and caregiver proxy ratings of quality of life was moderate, $(r[105] = 0.40, p < 0.001)$.

A series of one-way analyses of variance (ANOVAs) and independent t-tests were conducted (See tables 4.6 to 4.9) were completed in order to test the relationships between categorical moderators of interest and ratings of quality of life by both proxy raters and PwD.

Table 4.4

Measures Description: FAST Staging

Stage	Behavioural Symptom	Sample (*n* =107) *n* (%)
1	No difficulties, either subjectively or objectively	0 (0.0)
2	Complains of forgetting location of objects. Subjective word finding difficulties.	2 (1.9)
3	Decreased job function evident to co-workers; difficulty in traveling to new locations. Decreased organizational capacity.	15 (14.0)
4	Decreased ability to perform complex tasks (e.g., planning dinner for guests), handling personal finances (forgetting to pay bills), difficulty marketing, etc.	79 (73.8)
5	Requires assistance in choosing proper clothing to wear for day, season, occasion.	7 (6.5)
6a	Difficulty putting clothing on properly without assistance.	1 (0.9)
6b	Unable to bathe properly; e.g., difficulty adjusting bath water temperature) occasionally or more frequently over the past weeks.	1 (0.9)
6c	Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.	0 (0.0)
6d	Urinary incontinence, occasional or more frequent.	2 (1.9)
6e	Fecal Incontinence, (occasional or more frequently over the past week).	0 (0.0)
7a	Ability to speak limited to approximately a half dozen different words or fewer, in the course of an average day or in the course of an intensive interview.	0 (0.0)
7b	Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the word over and over.	0 (0.0)
7c	Ambulatory ability lost (cannot walk without personal assistance).	0 (0.0)
7d	Ability to sit up without assistance lost (e.g., the individual will fall over if there are no lateral rests [arms] on the chair).	0 (0.0)
7e	Loss of the ability to smile.	0 (0.0)

(Reisberg, 1984)

Table 4.5

Pearson Correlation Analysis: Relationship between Quality of Life Ratings and Potential Moderators

Moderator	Measure	Pearson Correlation with QOL-AD proxy rating	Pearson Correlation with QOL-AD PwD self-rating
Caregiver Burden	CBI Total Score	-0.47**	-0.07
Caregiver Age	Self-Reported Age	-0.04	0.07
ADL and iADL of PwD	DAD Total Score	0.56**	0.23*
Cognitive Impairment of PwD	MoCA Total Score	0.09	-0.05
Depressive Symptom Severity of PwD	CSDD Total Score (patient self-rating)	-0.18	-0.43**

* $p < 0.05$, ** $p < 0.01$

Rater Agreement

To answer the first research question posed for this project "What is the level of agreement between proxy raters and raters with PwD regarding PwD quality of life?" an ICC was calculated between PwD and caregiver proxies rating on the QOL-AD. To express the strength of agreement between raters the guidelines adhered to by Arons et al. (2013) was utilized. Wherein ICC values ranging between 0 to 0.20 represent slight agreement, 0.21 to 0.40 represents fair agreement, 0.41 to 0.60 represents moderate agreement, 0.61 to 0.80 represents substantial agreement, and 0.81 to 1.00 represents almost perfect agreement. Both absolute (interchangeability of raters) and consistency (association between raters' scores) agreement were determined. Calculating ICC consistency found fair agreement (ICC=0.39, 95% CI= 0.22 to 0.54) between PwD and caregiver proxy ratings on the QOL-AD. Fair agreement (ICC=0.30, 95% CI= 0.05 to 0.51) was also noted when determining absolute ICC.

Table 4.6

Independent Samples t-test: Difference of means between Quality of Life Ratings and Caregiver Education

| | Elementary and Secondary Education[a] | | | Post-Secondary Education | | | | | | |
Categorical Levels	*n*	Mean	Standard Deviation	*n*	Mean	Standard Deviation	95% Confidence Interval	*t*	Degrees of freedom	*p*
PwD Self-Ratings on the QOL-AD	46	33.9	5.7	61	34.6	7.3	-3.29 to 1.88	-0.54	105	0.48
Proxy Ratings on the QOL-AD	46	38.0	4.8	61	39.6	5.6	-3.63 to 0.48	-1.52	105	0.10

[a]Elementary Education and Secondary education combined due to small cell sizes.

$* p < 0.05, ** p < 0.001$

Table 4.7

Independent Samples t-test: Difference of means between Quality of Life Ratings and Caregiver Relationship to the PwD

| | Spousal Caregivers | | | Adult Child Caregivers | | | | | | |
Categorical Levels	*n*	Mean	Standard Deviation	*n*	Mean	Standard Deviation	95% Confidence Interval	*t*	Degrees of freedom	*p*
PwD Self-Ratings on the QOL-AD	54	38.9	5.2	42	39.1	5.3	-2.35 to 1.90	-0.54	94	0.83
Proxy Ratings on the QOL-AD	54	34.1	6.0	42	34.1	7.5	-2.86 to 2.80	-1.52	105	0.98

$* p < 0.05, ** p < 0.001$

Table 4.8

One-way ANOVA: Difference of means between Quality of Life Ratings and FAST staging

	FAST 2-3[a]			FAST 4			FAST 5			FAST 6a-6d[a]				
Categorical Levels	*n*	Mean	Standard Deviation	*n*	Mean	Standard Deviation	*n*	Mean	Standard Deviation	*n*	Mean	Standard Deviation	*F*	*p*
PwD Self-Ratings on the QOL-AD	17	40.2	3.9	79	38.7	5.8	7	38.9	3.2	4	36.5	5.3	0.64	0.59
Proxy Ratings on the QOL-AD	17	40.6	5.6	79	34	5.9	7	29.7	2.1	4	20.5	1.3	15.70	> 0.01**

[a] FAST levels of 2-3, and stages 6a, 6b as well as 6d were condensed due to small cell sizes.
* $p < 0.05$, ** $p < 0.001$

Table 4.9

One-way ANOVA: Difference of means between Quality of Life Ratings and PwD education

	Elementary			Secondary			Post-Secondary				
Categorical Levels	*n*	Mean	Standard Deviation	*n*	Mean	Standard Deviation	*n*	Mean	Standard Deviation	*F*	*p*
PwD Self-Ratings on the QOL-AD	17	37.5	6.4	47	39.7	5.1	43	38.6	5.3	1.14	0.32
Proxy Ratings on the QOL-AD	17	34.3	5.8	47	34.1	6.1	43	34.5	7.6	0.04	0.97

* $p < 0.05$, ** $p < 0.001$

Regression Analysis

Linear regressions were calculated to answer the second research "What factors moderate the relationship between proxy ratings and PwD ratings?" When conducting a linear regression it is generally advised to ensure of certain assumptions before attempting the analysis (Laerd Statistics, 2013). These assumptions will be discussed here. Firstly, the variables undergoing a regression analysis must be of a continuous nature and variables that are categorical must be dummy coded to adhere to this assumption. Secondly, a linear relationship should be present between variables. Indeed a scatterplot created comparing the ratings of quality of life between PwD and proxy for which points presented a linear relationship. Third, the dataset should be absent of significant outliers. As such the data has been combed through for potential data anomalies and checked visually by way of scatterplot. Another assumption necessary for a regression analysis is the independence of observations or the assumption that the happening of one event is independent of another event and will not affect it; this can be checked by way of the Durbin-Watson statistic. Durbin-Watson statistics were calculated for each regression computed and the values were consistently close to 2 which is indicative of independence of observations (Laerd Statistics, 2013). However, it is important to note that the participants recruited for the study were done so in pairs and therefore difficult to assert independence of observations. The next assumption checked for was that of homoscedasticity or similar variance across the line of best fit. This was visually confirmed by creating a scatter plot of the z-predictor variable (x-axis) and z-residual variable (y-axis) that did not reveal any patterns in the data. Lastly, the final assumption that required confirmation was the normal distribution of residuals or errors,

this was done by creating a histogram of residuals for every regression analysis. These steps were taken for every regression analysis conducted and each analysis adhered to every assumption presented above.

The results of the regression analyses for all variables are reported in Table 4.10. Table 4.10 shows the β's of the interaction terms that tested moderation in the 9 regression analyses. The table includes the Standard Error of the β's, their 95% Confidence Intervals, and statistical significance. The table also includes the R^2 of each regression model, including the main effect of the variable that was being tested for moderation. None of the hypothesized interaction effects significantly predicted PwD self-rated quality of life.

Table 4.10

Linear Regression Analysis: Interaction Terms of PwD-Caregiver Quality of Life Rating

Relationship

Moderator (tested as interaction term with PwD rated QOL)	Measure	β Estimation	β Standard Error	95% Confidence Interval	p Value of Interaction Term	R^2 of Full Model Including Main Effect
Caregiver Burden	CBI Total Score	0.002	0.008	-0.013 to 0.017	0.794	0.354
Caregiver Age	Self-Reported Age	-0.002	0.007	-0.016 to 0.012	0.805	0.166
ADL and iADL of PwD	DAD Total Score	0.006	0.005	-0.004 to 0.016	0.267	0.402
Cognitive Impairment of PwD	MoCA Total Score	0.008	0.018	-0.028 to 0.043	0.671	0.174
Depressive Symptom Severity of PwD	CSDD Total Score	-0.009	0.024	-0.055 to 0.038	0.710	0.163
Education of PwD[a]	Secondary Education	0.143	0.298	-0.449 to 0.734	0.634	0.195
	Post-Secondary Education	0.503	0.302	0.099 to 1.103	0.099	
Education of Caregiver[a] (socio economic status)	Post-Secondary Education	0.025	0.032	-0.039 to 0.089	0.441	0.167
Caregiver Relationship to PwD[b]	Child	0.416	0.240	-0.062 to 0.894	0.087	0.213
Behavioural Symptom Severity of PwD[cde]	FAST 4	-0.352	0.350	-1.046 to 0.343	0.317	0.435
	FAST 5	-0.526	0.734	-1.983 to 0.930	0.475	
	FAST 6	-0.772	0.660	--2.081 to 0.537	0.244	

[a] Reference level for Education of Caregivers was Elementary Education and Secondary education combined due to small cell sizes. Reference level for Education of PwD was Elementary education.

[b] Reference level for Caregiver Relationship to PwD was Spouse (Only spousal and Child relationships were compared).

[c] FAST levels of 1, and stages 7a through e were not reported and therefore analysis of these stages could not be completed.

[d] Reference level for FAST staging was FAST 2 and FAST 3 as well as FAST levels of 6a, 6b and 6d were combined due to small cell sizes.

* $p < 0.05$, ** $p < 0.001$

Chapter 5: Discussion

The goal of the current research endeavour was to answer the following two questions: (1) what is the level of agreement between proxy raters and PwD's self-ratings of quality of life? and (2) what factors moderate the relationship between proxy ratings and PwD ratings? In order to answer the first question, an ICC was calculated to determine agreement between PwD and proxy raters. There was fair agreement between proxy and PwD ratings of quality of life. To answer the second question, a series of linear regressions were conducted predicting PwD rated quality of life with hypothesized moderator variables, proxy ratings of QOL-AD, and interaction effects. The findings of these analyses yielded no significant findings and, therefore, suggest that none of the hypothesized variables play a moderating role in the relationship between proxy and PwD self-ratings of quality of life.

Before interpreting where the current findings fit into the current caregiving literature, the sample utilized for this project and underlying relationships should be characterized and understood for its place in the rating moderator literature. The Canadian sample consisted largely of female caregivers (69%) and PwDs (55%). Similar to samples found in the literature, caregivers were typically female, however the majority of PwDs in comparable literature were typically male (Arons et al., 2013; Crespo et al., 2011; Conde-Sala et al., 2010; Moyle et al., 2011; Tay et al., 2014). The PwDs commonly reported completing high school (44%) while their caregiver counterparts were typically university/college educated (57%). Caregivers reported greater education than PwDs in other published samples (Conde-Sala et al., 2010; Schulz et al., 2013; Tay et al., 2014)

Predominantly, both PwDs and their caregivers resided in their own abodes (85% and 96% respectively) with the dyads typically living with one another (70%). Moreover, the sample was predominantly English speaking (94%) and consisted of mostly spousal (51%) and adult child (39%) caregivers. All studies reviewed were of English speaking samples that consisted entirely of either spousal or child caregivers, or were comprised largely of the two groups (Arons et al., 2013; Crespo et al., 2011; Conde-Sala et al., 2010; Moyle et al., 2011; Schulz et al., 2013; Tay et al., 2014).

Caregivers rated provided lower proxy ratings of quality of life than the PwDs own self-ratings. Indeed, in the literature, significant differences have been noted between patient self-ratings of quality of life and family caregiver proxy ratings, with the former typically rated as higher on quality of life assessments, in line with the findings of this project (Crespo et al., 2012; Novella et al., 2001; Sheehan et al., 2012). Caregivers provided with the CBI reported a mean score of 19.8. This average score for caregiver is below what is thought to require respite care for caregivers (CBI score > 24) or risk "burning out" (CBI score > 36; Western University, 2010a).

The average MoCA score of the recruited PwDs was 17.1, a score which the creators of the assessment tool suggest is indicative of moderate cognitive impairment (Moca Montreal Cognitive Assessment, 2015). Of the studies reviewed, PwD cognitive impairment among participants usually ranged from mild to moderate among those that reported it (Crespo et al., 2011; Moyle et al., 2011; Zhao et al., 2012). Tay et al. (2014), however, excluded PwDs who exhibited even mild cognitive impairment. The PwDs recruited to this study completed the CSDD with a mean score of 3.9. A score below 6 on the CSDD is indicative of the absence of clinical depression (Western University, 2010b).

Of the studies reviewed that reported PwD depressive symptoms, the majority of PwD

participants did not exhibit symptoms indicative of clinical depression (Gomez-Gallego

et al., 2015; Schulz et al., 2013; Tay et al., 2014; Zhao et al., 2012). The FAST was

utilized to assess dementia staging in this project with PwDs predominantly exhibiting

the stage 4 of 7 (74%) which is suggestive of mild dementia (Scalan & Reisberg, 1992).

All the studies reviewed reported utilizing a sample of PwDs who met criteria for

"milder" dementia (Arons et al., 2013; Bosboom et al., 2012; Crespo et al., 2011; Conde-

Sala et al., 2010; Gomez-Gallego et al., 2015; Moyle et al., 2011; Schulz et al., 2013; Tay

et al., 2014; Zhao et al., 2012). In summation, the sample recruited for the current study is

similar in a demographic and clinical nature to that reported by other relevant studies

observing potential moderators and relationships that may influence the PwD and proxy

rating relationship.

In order to understand the underlying relationships of potential moderators of both

categorical and continuous nature with quality of life ratings of proxies and PwD, both

Pearson correlations and one-way ANOVAs were conducted. The correlational analysis

conducted found significant positive correlations between scores on the DAD and total

scores on the QOL-AD provided by PwDs (r[105] = 0.56, $p < 0.01$) and proxy raters

(r[105] = 0.23, $p < 0.05$). The positive moderate correlation between of DAD scores and

PwD QOL-AD scores as well as the positive weak correlation of DAD scores and proxy

QOL-AD scores are representative of greater DAD scores or the PwDs ability to

complete activities of daily living to be associated with greater ratings of quality of life.

Moyle at al. (2011) also noted an association between activities of daily living and PwD

scores on the QOL-AD. In line with our correlational analysis, these researchers reported

reduced quality of life to be associated with greater difficulty in completing activities of daily living (Moyle et al., 2011). Contrary to the findings of the correlational analysis conducted, Bosboom et al. (2012) reported an inverse association between PwD scores on the QOL-AD and scores on activities of daily living.

The completed correlational analyses for this project also found total scores for the CBI (representative of caregiver burden) and proxy rated QOL-AD to be significantly associated (r[105] = -0.47, $p < 0.01$). This observed relationship was moderate in nature and the variables were inversely associated. That is, greater burden reported by the caregivers was associated with poorer proxy ratings of quality of life. Inverse moderate correlations between proxy ratings of quality of life and caregiver burden were noted by Conde-Sala et al. (2010) across different types of familial caregiver including sons, daughters, wives, and husbands. Schulz et al. (2013) also reported a moderate inverse correlation between the two variables.

Lastly, a significant correlation was observed between CSDD scores, representative of PwD depressive symptoms, and PwD self-ratings of quality of life (r [105] = -0.43, $p < 0.01$). The negative correlation was moderate in strength. Bosboom et al. (2012) reported significant negative correlations between PwD depressive scores and PwD ratings of quality of life. The correlations were weak among dyads in which PwDs rated quality of life higher than their proxy counterparts and strong among dyads where PwDs rated their quality of life lower than that reported by proxies (Bosboom et al., 2012). It is important to note that while scores on the DAD exhibited stable positive correlations across both PwD and proxy ratings, CBI and CSDD scores differed. Burden was significantly associated with proxy ratings and PwD depressive symptoms with PwD

self-ratings. Burden of the caregiver was implicit and difficult to perceive for the PwD, possibly making it difficult for the PwD to perceive this and any impact it may have on their self-rating of quality of life. Similarly, PwD depressive symptoms are not explicit and not always readily apparent to their caregivers. Caregiver burden and PwD depressive symptoms are salient respectively to the caregiver and PwD themselves, thereby possibly explaining the significant correlational relationships.

A series of one-way ANOVAs were also conducted to determine differences between mean quality of life scores of proxy raters and PwDs across the hypothesized categorical moderators. The only significant difference between means noted in the current findings, was that between proxy ratings of quality of life and varying stages of the FAST. The ANOVA conducted was suggestive of proxy quality of life ratings decreasing as the PwD progressed to later stages of dementia, in accordance with the FAST. Of the studies that sought to understand factors that may play a role in the PwD-proxy rating relationship, those that presented other forms of analysis to understand the underlying relationships of potential moderators seem to generally coincide with those present in the current study.

It is important to discern how the main findings answering the proposed research question compare to relevant preceding literature on proxy and PwD ratings, regarding agreement between the two parties and factors that may moderate the rating relationship. In answering the first research question "What is the level of agreement between proxy raters and PwD's self-ratings of quality of life? Fair consistency agreement (ICC = 0.39, 95% CI = 0.22 to 0.54) between the two rating parties was noted, as well as fair absolute agreement (ICC = 0.30, 95% CI = 0.05 to 0.51). Many of the studies reviewed that

observed the proxy and PwD rating relationship, reported ICC values of agreement. Arons et al. (2013) utilized the EuroQOL 5-dimensions to measure quality of life and reported slight agreement (ICC = 0.18) on the visual analogue scale and fair agreement (ICC = 0.50) on the utility measure between PwD and proxy raters. Another study observed agreement for spousal caregivers and adult child caregivers with the PwD self-reported quality of life on the QOL-AD (Conde-Sala et al., 2010). The researchers reported fair absolute agreement (ICC = 0.34, 95% CI = 0.11 to 0.52) and consistency agreement (ICC = 0.31, 95% CI = 0.11 to 0.52) between spousal proxies and PwD self-rated quality of life (Conde-Sala et al., 2010). Conde-Sala et al. (2010) also noted reported fair absolute agreement (ICC = 0.31, 95% CI= 0.10 to 0.48) and consistency agreement (ICC = 0.37, 95% CI = 0.21 to 0.50) between adult child proxies and PwD ratings of quality of life. Moyle et al. (2011) observed fair agreement in both consistency agreement consistency (ICC = 0.30, 95% CI = 0.14 to 0.47) and absolute agreement (ICC = 0.27, 95% CI = 0.17 to 0.44) between proxy and PwD ratings on the QOL-AD. Similarly, Tay et al. (2014) reported fair agreement in both absolute agreement (ICC= 0.22, 95% CI = 0.06 to 0.38) and consistency (ICC = 0.27, 95% CI= 0.12 to 0.41) on ratings of the QOL-AD. Lastly, Zhao et al. (2012), noted moderate agreement between PwD and proxy raters on the QOL-AD (ICC = 0.58, 95% CI = 0.41 to 0.71). This review of the literature on proxy and PwD rater agreement found it to range from slight to strong agreement on both the EQ-5D and QOL-AD measures of quality of life. The majority of studies reviewed utilized the QOL-AD, as was done in this study as well, and were found to report fair agreement, similar to the findings of the thesis research.

In answering the second research question "What factors moderate the relationship between proxy ratings and PwD ratings?" a series linear regression analyses within a moderator framework found no significant interaction effects for any of the hypothesized moderators. These hypothesized moderators included caregiver burden, caregiver age, caregiver income, PwD ADLs/IADLs, PwD education, PwD cognitive impairment, PwD depressive symptom severity, PwD behavioural symptom severity, and the relationship between caregiver and PwD. The moderator analysis findings of this project are largely contradictory to those found in the literature. Three of four studies reviewed which examined predictors of differences between proxy and patient ratings found that caregiver burden was associated with rating discrepancy, which is suggestive of a moderating relationship (Gomez-Gallego et al., 2015; Schulz et al., 2013; Zhao et al., 2012). The relationship between caregiver burden and quality of life rating discrepancy reported by the literature was the increase of burden to be associated with greater rating difference between proxy and PwD raters. The fourth study, conducted by Tay et al. (2014) found that after controlling for the effects of age, gender, caregiver education, PwD depression, and PwD behavioural symptoms, caregiver burden was not associated with discrepancy. Though these authors' findings coincide with those observed in this project, it is important to note that the thesis research did not control for the effects of other variables. Furthermore, in the research conducted by Tay et al. (2014), it is important to note that once variables such as PwD behavioural symptoms and PwD depression were controlled for there is little variance for caregiver burden as the variables are inter-related. Therefore controlling for these variables may eliminate a potentially observed relationship.

Also contradictory to the null findings of this study, Schulz et al. (2013) reported caregiver socioeconomic status to be associated with rating discrepancy, with greater caregiver socioeconomic status associated with worse agreement.

One study noted spousal proxy ratings to be greater than adult child ratings of quality of life, indicating that kin relationship between caregiver and patient may influence proxy ratings (Conde-Sala et al., 2009). These same researchers in a later study noted better agreement between spousal caregivers and patients than adult child caregivers and patients (Conde-Sala et al., 2010). The present study found no significant effect from the moderator analysis between caregiver relationship to PwD and proxy-PwD rating relationship.

Caregiver age was also noted in the literature as predictive of caregiver proxy ratings, suggesting some form of relationship with the proxy-PwD rating relationship (Arons et al., 2013). Arons et al. (2013) proposed older caregivers may provide better proxy ratings of quality of life than younger caregivers. Age was not found to play a moderating role in the rating relationship within the present sample.

Both Tay et al. (2014) and Zhao et al. (2012) observed the behavioural symptoms of PwD found them to be associated with rating discrepancy. These studies reported greater symptom severity to be associated with greater rating discrepancy (Tay et al., 2014; Zhao et al., 2012). No significant finding was noted in the moderator variable analysis pertaining to behavioural symptom severity (FAST staging).

Two studies that observed PwD depressive symptoms reported it to be associated with rating disparity (Gomez-Gallego et al., 2015; Tay et al., 2014). Lower depressive

symptom severity was associated with greater rating discrepancy (Gomez-Gallego et al., 2015; Tay et al., 2014). A study also reported activities of daily living and instrumental activities of daily living such as housework, meal preparation, financial management and shopping were also reported to be associated with rating discrepancy (Bosboom et al., 2012; Moyle et al., 2011; Zhao et al., 2012). Lower functional/instrumental activity was associated with greater rating difference (Bosboom et al., 2012; Moyle et al., 2011; Zhao et al., 2012). In the current study, neither PwD depressive symptoms nor PwD activities of daily living were observed to play a moderating role in proxy-PwD quality of life rating relationship.

Lastly, a study also observed PwD education and cognitive impairment to be associated with rating disparity (Tay et al., 2014; Zhao et al., 2012). With greater education and less cognitive impairment associated with greater rating disparity (Tay et al., 2014; Zhao et al., 2012). Both variables were not observed to moderate the rating relationship.

Contrary to the findings of relevant literature, all hypothesized moderator variables were not found to exhibit a significant effect from the moderator regression analysis. Therefore it is important to understand what factors, issues, and potential biases at differing levels of the research process, such as sampling, measurement, and analysis, that may have resulted in dissimilar findings from those posed in the literature.

With regard to sampling, the participants recruited for the present study appear to comparable to the samples reporting in relevant dementia quality of life rating literature.

As evidenced earlier in this chapter, the demographic and clinical nature of the current sample is similar to those in relevant studies.

The measurement for the current research project also exemplified that found in similar research studies. Indeed, the predominant measure of choice in the literature to assess quality of life was the QOL-AD, which was utilized in the present study (Bosboom et al., 2012; Crespo et al., 2011; Conde-Sala et al., 2010; Moyle et al., 2011; Schulz et al., 2013; Tay et al., 2014; Vogel et al., 2006). When assessing caregiver burden, researchers typically utilized the Zarit Burden Inventory, contrary to the use of the CBI for the purposes of this study (Gomez-Gallego et al., 2015; Schulz et al., 2013; Zhao et al., 2012). However, Conde-Sala et al. (2010) utilized the CBI for the purposes of their proxy-PwD rating analyses. Of the two studies that observed PwD depressive symptoms and its relationship to rating discrepancy, one utilized the CSDD as did the current project; the other employed the Zarit Burden Inventory (Gomez-Gallego et al., 2015; Tay et al., 2014). The studies that reported a relationship between ADLs/IADLs utilized the PAQUID modified instrumental activities of daily living, Physical Self-Maintenance Scale, or Katz's Activities of Daily Living scale; none of the referred to studies utilized the DAD which was employed in the current thesis project (Bosboom et al., 2012; Moyle et al., 2011; Zhao et al., 2012). Lastly, behavioural symptom severity and cognitive impairment were typically assessed in the relevant literature utilizing the Neuropsychiatric Inventory and the Mini Mental State Exam, whereas the current study employed the FAST to assess behavioural symptoms and the MoCA for cognitive impairment (Tay et al., 2014; Zhao et al., 2012). As such, though certain measures seem universally employed such as the QOL-AD, other measures utilized to assess potential

moderators were not as typical. The measures utilized for this research project were psychometrically robust as stated earlier in a review of the literature and the estimate of reliability conducted for this study found reliability of test scores as assessed by Cronbach's alphas ranging from 0.85 to 0.92.

The analyses conducted shared similarities to those conducted in the relevant literature while also differing in other manners. When assessing agreement between proxy and PwD ratings of quality of life, relevant literature typically utilizes an ICC to determine agreement (Arons et al., 2013; Conde-Sala et al., 2010; Moyle et al., 2011; Tay et al., 2014; Zhao et al. 2012). Moreover, when assessing factors that may be associated rating discrepancy, linear regressions were conducted quality of life ratings provided by proxies and PwD along with any hypothesized variables (Bosboom et al., 2012; Conde-Sala et al., 2010; Schulz et al., 2013). However, to conduct a moderator variable analysis and determine the presence of a moderator variable, interaction effects must be created between independent variables and potential moderators to which then impute into a linear regression. This methodology was created by Baron and Kenny (1986) and become recognized as the standard in determining and evaluating moderator variables (Jose, 2013). No study reviewed employed a moderator variable analysis and therefore may be a potential reason for significant findings of reported factors influencing proxy-PwD ratings in the literature and a lack of similar findings in the current study. Moreover, as this study sought to determine the presence of moderator variables, it may be that the relationships observed in the literature are of a different nature than moderation. The relationship may be mediated moderation, thus explaining the small interaction effects and the review of the literature suggesting the presence of moderation.

Lastly, the lack of observed significant findings for the current study may be due to the presence of a Type II or Type III error. There are three types of errors that may be committed when conducting research. The first is incorrect rejection of a true null hypothesis, that is the researcher may report a significant relationship exists when in truth no such relationship exist, known as a Type I error (Polit et al., 2010). The second is the incorrect acceptance of a false null hypothesis, that is the researcher reports no significant relationship exists when in truth a relationship does exist (Polit et al., 2010). Lastly, the third type of error is one wherein the researcher provides the right answer to the wrong question (Schwartz & Carpenter, 1999). The risk of a Type 2 error occurring are due to smaller sample sizes, measurement quality, or strength of underlying relationships between variables (Polit et al., 2010). Both measurement quality and small effects have been noted to be robust by way of relevant literature referred to earlier in the section and analyses conducted within the framework of this study. As such, the sample size of this study ($N = 107$) may have contributed to potential Type II error. When determining necessary sample sizes for regression analyses, there are several rules of thumb. Some sources consider a total sample of 100 participants to be adequate and 200 to be good, while others prefer utilizing the 104+k or 50+8k rules of thumb, where k is representative of the number of independent variables to be imputed into the regression analysis (Green, 1991). For the current project the value of k was typically 3, and therefore met adequate sample size to conduct linear regressions in accordance with all three guidelines. Therefore, the lack of significant interaction effects may be due to a type III error; that is the wrong question was posed to understand the proxy-PwD rating relationship (Schwartz & Carpenter, 1999). Instead of examining moderation solely perhaps exploring other

relationship archetypes may be beneficial such as mediation or into more complex relationships such as mediated-moderation or moderated-mediation. Directing this study in a different analytical direction may have provided greater insight into the proxy-PwD rating relationship.

It is important to discuss the research and clinical ramifications of the current thesis project. Quality of life agreement between PwD and proxy raters for this research project is consistent with that found in the literature; while this does contribute any to new avenues of inquiry it does reaffirm existing observations in relevant research. The findings of the moderator analysis however, are more novel and suggest none of the hypothesized variables play moderating roles. Though these variables may not moderate the PwD-proxy rating relationship regarding quality of life, the may influence the relationship in another capacity. As such, other forms of analyses should be undertaken to identify and understand in what scope these variables influence the rating relationship. From a clinical perspective, a practitioner or health worker should be cautious of relying solely on proxy ratings when assessing PwD quality of life due to only fair agreement being observed between PwD and proxy raters. Moreover, the findings of the moderator variable analysis suggest that the clinician should not contemplate the influence of the hypothesized variables as moderators. However, the healthcare worker should still hold these variables in some regard when assessing quality of life either by proxy or self-report, as a great deal of literature does support their influence on the proxy-PwD rating relationship.

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