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KEY PREDICTORS OF WELL-BEING FOR INDIVIDUALS WITH DEMENTIA

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Bachelor of Arts in Psychology

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# KEY PREDICTORS OF WELL-BEING FOR INDIVIDUALS WITH DEMENTIA

LINDSEY M. BISGROVE

## ABSTRACT

Until recently, few studies have investigated the psychosocial outcomes of individuals living with dementia. More specifically, the relationship among depression, anxiety, and quality of life as well-being outcomes. The current study examined the role of well-being outcomes and how key predictors (level of cognitive impairment, level of distress experienced, relationship role strain) influenced these outcomes. It addressed how these specific predictors had an impact, on depression and anxiety symptoms and overall quality of life. This study utilized the stress process model for individuals with dementia as a framework to demonstrate the intricacies of the illness experience for the individuals. Self-report data was used from IWDs (N = 131) about their illness experience.

*Keywords:* dementia, predictors, psychosocial outcomes, stress process model, illness experience

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# **CHAPTER I**

## **INTRODUCTION**

### 1.1 Background and Purpose

Dementia is a neurodegenerative condition that has a negative impact on social and cognitive levels of functioning (Jalbert et al., 2008). It is characterized by the deterioration in cognition and memory, progressive impairment in the ability to carry out activities of daily living, and multiple neuropsychiatric symptoms (Jalbert et al., 2008). Few studies have examined the illness experience of living with dementia. Specifically, little is known about key well-being outcomes (i.e. symptoms of depression, symptoms of anxiety, and quality of life), and how they may be impacted by other aspects of the illness experience, such as cognitive impairment. The current study addressed these gaps in the literature. The following sections detail the literature pertaining to this area.

### 1.2 Impact of Dementia

Research has found that dementia not only affects the individuals, but also affects their informal family caregivers and society (Mattei et al., 2009). Currently there is no

cure for dementia or readily accepted pharmacological treatment protocol. Dementia, in general and in its most common form of Alzheimer's disease, has become a major health concern worldwide, especially as the population ages (Simard, Hudon, & Van Reekum, 2009). Subsequently, dementia has a negative and cost prohibitive impact on healthcare systems. For example, long-term care and medical costs impact a wide range of services including Social Security to insurance programs (Plassman et al., 2007). It also is apparent that dementia has a distinct impact on relationships between the patients with dementia and their caregivers (Ablitt, Jones, & Muers, 2009). Taking care of individuals with dementia (IWDs) has the potential to affect caregivers' physical and psychological health, along with creating a financial burden. In fact, because of the growing awareness of the impact of dementia on caregivers, one limitation of current research is that it does not specifically address the IWD's experience (Anthony-Bergstone & Zarit, 1988).

### 1.3 Living with Dementia

Until recently, few studies have investigated the psychosocial outcomes of individuals with dementia (Scholey & Woods, 2003; Seignourel et al., 2008). Since individuals each have their own illness experience, it is important to address well-being outcomes and what affects them (Kitwood, 1997). Studies that have been done in regard to psychosocial outcomes have focused on information provided by the perspective of the caregiver or from proxy reports from clinicians in understanding the illness experience of individuals with dementia. Thus few studies have collected information directly from the IWD (Ablitt, Jones, & Muers, 2009). It is important to use information from the IWD because studies have shown that caregivers and clinicians may not provide a complete,



accurate assessment of the individual's experience. A study conducted by Arlt and colleagues concluded that caregivers underestimated the IWD's QoL and clinicians mainly only focused on the patient's severity of cognitive impairment instead of addressing all of the aspects of dementia (2007). Their research has shown that patients are important informants about their illness experience and their perspective should be used as the "golden standard" when obtaining a comprehensive understanding of the patient's well-being (Arlt et al., 2007).

Not including experiences from the IWD, or having lack of insight, may lead to an underestimation of symptoms. This may be because some symptoms patients experience are cognitive in nature and may be difficult to evaluate through standard self-report measures (Ferretti et al., 2001). Several studies have shown that patients are able to give precise insight on their feelings and experiences (Arlt et al., 2007). For example, a study conducted by Hoe and colleagues found individuals with severe symptoms of dementia were capable of rating their own quality of life (QoL) when using standardized measures (2005). Results indicated IWDs with a Mini-Mental State Examination (MMSE) score of 3 or more were able to rate their QoL using the QoL scale in Alzheimer's disease (QoL-AD) (Hoe et al., 2005). Expanding on this study has shown there is now ample evidence to support the inclusion of IWDs in the research and treatment process, as they are able to provide accurate information regarding their illness and experiences (Hoe et al., 2005; Kitwood, 1997). Subsequently, utilizing more accurate information can lead to a better understanding of the dementia experience, which can lead to better treatment options and methods.

Understanding the illness experience from the perspective of the IWD also would

highlight key psychosocial areas amenable to non-pharmacological interventions. This shift potentially would facilitate the prevention of anxiety symptoms and depression symptoms, and assist with earlier diagnosis in order to help individuals have a better experience throughout their illness (Simard, Hudon, & Van Reekum, 2009). A review performed by Simard, Hudon, & Van Reekum showed there is a need for a comparison of the various symptoms experienced by IWDs in order to adapt treatments for specific patient populations (2009). Previous research has indicated how important it is to recognize how individuals with dementia are affected by, and cope with, the symptoms of depression and anxiety (Simard, Hudon, & Van Reekum, 2009). Anxiety and depression have been linked with poor QoL and problem behaviors (Seignourel et al., 2008). Addressing these various symptoms may help determine why patients are experiencing certain emotions through the dementia process. Along with these specific symptoms, it also is important to determine potential predictors. One issue related to understanding symptoms of anxiety and depression is the ability to measure and disentangle these constructs in IWDs (Seignourel et al., 2008). Insight into these constructs is significantly needed and has the potential to assist in the refinement and development of assessment measures and interventions (Seignourel et al., 2008). For example, it may be that by attending to and changing the predictors directly, patients may experience less anxiety or depression symptoms, which could cause an overall better QoL.

Depression and anxiety symptoms are unique variables that affect the quality of life (QoL) in IWDs (Seignourel et al., 2008). Seignourel and colleagues found that defining these variables in IWDs is complex due to the overlap between the individual symptoms of anxiety, depression, and dementia (Seignourel et al., 2008). Specifically, it

is important to address what contributes to depression and anxiety, and how these disorders affect overall quality of life. In addition, it is essential to look at what factors have the ability to predict effects on depression, anxiety, and QoL. Few attempts have been made to assess the combined and separate well-being outcomes in IWDs. In addition, few attempts have taken predictive factors into consideration, such as key factors related to the illness experiencing including level of cognitive impairment, level of personal activities of daily living (PADL) distress experienced, level of instrumental activities of daily living (IADL) distress, level of relationship strain, and role captivity. Further research is needed to explain the illness experience from the perspective of IWD to make sure that interventions are properly targeting important well-being outcomes. The knowledge that can be gained by examining previous and current research has the potential to improve and develop future care practices and new intervention techniques. One of the current limitations is the lack of a conceptual model that delineates the illness experience of IWDs. The following section will detail literature pertaining to the proposed conceptual model.

#### 1.4 Stress Process Model (SPM) for IWDs

The majority of previous research has been focused around medical models, instead of using models that address the social and emotional aspects of an illness. Medical models have not emphasized possibilities and options for IWDs. In addition, these models do not properly examine the illness experience of the IWDs from their perspective. The current study used the stress process model for individuals with dementia (SPM for IWDs). This conceptual model focuses on the stress and well-being of

IWDs (Judge, Menne, & Whitlatch, 2009). It demonstrates the intricacies of the illness experience for the individuals by showing how various stressors are able to impact the individual's experience in many different ways. Specifically, there are five key areas of the SPM for IWDs and include: (1) Background and Context Characteristics, (2) Objective and Subjective Primary Stressors, (3) Role and Intrapsychic Secondary Strains, (4) Internal and External Mediators, and (5) Outcomes of Well-being (Judge, Menne, & Whitlatch, 2009). The SPM for IWDs posits that "primary stressors" have an impact on "secondary strains" (Judge, Menne, & Whitlatch, 2009). Secondary strains occur as a direct result of living with dementia. These secondary strains have the potential to have direct and indirect effects on "outcomes of well-being". "Internal and external mediators" are capable of buffering the relationships between primary stressors, secondary strains, and outcomes of well-being (Judge, Menne, & Whitlatch, 2009). The SPM for IWDs provides a framework for including interventions as internal and external mediators. A result of this is that the interventions may offset the negative effects of the stress process. In addition, they have the potential to enhance the IWD's care situation (Judge, Menne, & Whitlatch, 2009).

In the current study, the SPM for IWDs was used in order to examine the factors that are predictive of the IWDs' illness experience and psychosocial outcomes. Using this model, the five specific predictors investigated were level of cognitive impairment, level of PADL distress experienced, level of IADL distress experienced, relationship strain, and role captivity. Along with examining the effect of these predictors, the resulting strains and psychosocial effects were also observed.

It may be that the SPM for IWDs could be used to show how symptoms of

depression and anxiety, or how an IWD's QoL, may be influenced by a combination of the IWD's level of cognitive impairments, level of PADL and/or IADL experienced distress, relationship strain, and role captivity. This example shows how there can be an interaction between multiple stressors. It also shows how stressors can mutually have an influence on well-being outcomes, which is why it is important to examine the effect that predictors have. This shows that the SPM for IWDs provides a logical method for examining complex interactions and associations (Judge, Menne, & Whitlatch, 2009). Currently limited research exists using the SPM for IWDs as a conceptual model and whether specific variables predict the experience of well-being outcomes for IWDs. The following sections will detail literature pertaining to the well-being outcomes depression, anxiety, and QoL.

### 1.5 Depression

Depression is common in dementia (Scholey & Woods, 2003). Studies have reported observing a range of 14-87% of patients meeting the criteria, or diagnosed, with Alzheimer's disease that presented depressed moods (Scholey & Woods, 2003). Most of the variation in the percentage reported can be accounted for by the sampling technique used by each specific study. Currently, if depression is detected, effective treatments are available (Arlt et al., 2008). A study conducted by Arlt et al (2008) examined depression in IWDs through self- and proxy-ratings. The study suggested individuals with mild to moderate dementia were able to properly assess their depressive symptoms. Research also has found a close relationship between aggression and depression, which highlights the link between mood and cognition (Ownby, Harwood, Barker, & Duara, 2000). This

link may be exceedingly important in terms of refining, or even in developing, interventions for IWDs. For example, if there is a close relationship between mood and cognition, perhaps intervening upon depression can result in intervening on other neuropsychiatric symptoms that have been reported in patients. These linkages, or highlights, may also be able to point out potential predictors that could have an effect on depression symptoms. Unfortunately, treatment interventions are under-developed for IWDs who experience depression (Scholey & Woods, 2003). A major development in intervention techniques is that there is now a growing awareness of the significance of the perspectives of the IWDs.

The study previously mentioned that was conducted by Arlt et al was comprised of patients who had mild to moderate dementia. Using the MMSE along with the self- and proxy-ratings, they investigated depression and cognitive impairment in regard to how the ratings of the patients, caregivers, and clinicians related to one another. The study concluded that patients' ratings concerning depression correlated with the clinician's evaluation (Arlt et al., 2008). This provides evidence to support the notion that patients can provide accurate facts about their condition. It also shows that IWDs are important informants in their illness experience.

This shift of attention to the IWD's perspective can now focus on the many changes and losses that IWDs experience, which have the potential to lead to depressive symptoms (Cheston, Jones, & Gilliard, 2003). Scholey and Woods (2003) found that depressive symptoms can have a simple cause and can be due to events as straight forward as the loss of mobility or daily living skills. Recent studies have found success by addressing the subjective experience for the IWDs and by examining their

interpersonal relationships (Scholey & Woods, 2003). These results provide support as to why it is important to use self-report data and look at multiple moderating factors that could potentially be influencing a patient's illness. Encouraging the use of a variety of different strategies to facilitate adjustment to impairments has been found to improve psychosocial interventions, in regard to addressing IWDs who experience depression symptoms. This may be due to opening the lines of communication for individuals to report their own feelings and experiences.

## 1.6 Anxiety

Epidemiological studies have concluded that anxiety is common in older individuals (Seignourel et al, 2008). Experiencing anxiety is more common in individuals with dementia than it is in individuals without dementia (Paukert et al., 2010). Specifically, in patients with dementia, prevalence rates range from 8-71% for anxiety symptoms (Seignourel et al., 2008). As previously stated, the variation in these rates may be accounted for by the sampling techniques that were used in the individual studies. Ownby et al (2000) state that even though anxiety symptoms have been found to increase the likelihood that patients will receive health care services, relatively little is known about the correlates of anxiety symptoms in IWDs. Anxiety has been found to have a significant, negative impact on the individuals' functioning, and has been associated with poorer QoL and behavioral disturbances, even when controlling for depression (Paukert et al., 2010). Defining anxiety in IWDs is complicated by the overlap between symptoms of anxiety, depression, and dementia (Seignourel et al., 2008; Ferretti et al., 2001).

There is a lack of consensus on how to define and conceptualize anxiety symptoms, which contributes to the difficulty of disentangling the different symptoms IWDs experience. Anxiety in IWDs is significantly associated with more symptoms of depression, worse QoL, behavioral disturbances, increased cognitive impairment, limitations in daily activities, and increased risk of nursing-home placement (Seignourel et al., 2008; Ferretti et al., 2001; Paukert et al., 2010). Potential predictors for symptoms of anxiety still need to be examined. Unfortunately, little is known about the development and progression of anxiety in IWDs (Ferretti et al., 2001).

Anxiety symptoms are cognitive in nature and may be difficult to evaluate through standard self-report measures. Previous studies have emphasized how important it is to assess for moderating factors that influence the risk for developing anxiety symptoms in patients with dementia (Ferretti et al., 2001). Ownby and colleagues (2000) collected data from assessments of IWDs ages 65 years and older. They evaluated the data to investigate the prevalence of anxiety symptoms in patients and to establish what factors may be related to them. There were 133 patients included in the analysis, with 62.4% rating as either having anxiety regarding upcoming events, other anxieties, or both. The analysis concluded that anxiety symptoms are common in patients with dementia, but that there is a clear need for more precise evaluations of anxiety and the moderating factors (Ownby, Harwood, Barker, & Duara, 2000).

As with other psychosocial outcomes, assessments and treatment interventions are under-developed for IWDs who experience anxiety (Seignourel et al., 2008). Prior research has struggled over what constitutes the best source of information (e.g. the patient, caregiver). In the general population, the most common source of information is



the patient himself. As dementia progresses, however, some patients have difficulty communicating and remembering their symptoms. Nevertheless, there are symptoms that the caregiver may not be aware of (worrying, trouble concentrating, difficulty controlling feelings), so self-report data is immensely important in order to address the IWD's illness experience (Seignourel et al., 2008). Also, a considerable amount of anxiety symptoms are nonspecific and can have common characteristics with other psychiatric syndromes that are frequently seen in dementia, such as depression (Ferretti et al., 2001).

### 1.7 Quality of Life (QoL)

Quality of life is a complex, multidimensional construct (Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2010). QoL incorporates cognitive, emotional, physical, and social functioning and lifestyle, along with activities of daily living (Hoe et al., 2005; Logsdon et al., 2002). Poor QoL has been associated with agitation, depression, psychosis, psychomotor agitation, and psychotropic drug use (Wetzels, Zuidema, Jonghe, Verhey, & Koopmans, 2010). Additionally, depressive symptoms are strongly associated with a negative QoL (Logsdon, Gibbons, McCurry, & Teri, 2002). In 2010, Wetzels and colleagues conducted a study to assess determinants of QoL in nursing home patients who had dementia. The study included 288 IWDs from 14 special care units in 9 nursing homes. Results showed that agitation and depression were predominantly strong predictors of poor QoL. Along with agitation and depression, neuropsychiatric symptoms, decreased activities of daily living, and comorbid psychosocial symptoms have been found to negatively influence QoL in IWDs (Wetzels, Zuidema, Jonghe, Verhey, & Koopmans, 2010). Another important aspect is that previous research has

shown that there are interpersonal differences in how dementia is experienced (Kitwood, 1997; Van Mierlo, Van der Roest, Meiland, & Droes, 2010).

As with other psychosocial outcomes, it has been suggested that the patient's subjective ratings should be the standard (Hoe et al., 2005; Kitwood, 1997). A study conducted by Arlt and colleagues (2008) on one hundred outpatients with mild to moderate dementia and their family caregivers showed that assessing the patients' perspectives is needed in order to fully understand the patients' well-being. Self-report data is especially helpful since knowledge about patients' non-cognitive features is highly limited (Ferretti et al., 2001). Observational ratings should be used in cases where patients have more severe dementia, but also can be used to create a better overall picture of an individual's QoL in the mild to moderate levels of functioning (Arlt et al., 2008).

Logsdon et al (2002) state that QoL ratings can be used in order to determine whether or not a specific intervention has had a significant impact. They concluded that these scales can help determine the extent to which a treatment has been beneficial to patients, and whether or not the interventions have offered their intended assistance (Logsdon, Gibbons, McCurry, & Teri, 2002). Due to the results that QoL scales can potentially offer, they are particularly important in older individuals for assessing the efficacy and effectiveness of interventions. In particular, quality of life is primarily used as an outcome variable to explain the illness experience for the IWDs (Arlt et al., 2007).

Individuals with mild to moderate dementia can rate their own QoL with high reliability and validity. Prior research has shown that, even with varying levels of dementia, individuals have demonstrated the ability to rate their own QoL when using standard measures (Hoe et al., 2005; Logsdon et al, 2002; Selwood et al., 2005). Hoe et al

(2005) examined the usefulness of the QoL scale in Alzheimer's disease (QoL-AD) in patients with severe dementia (defined by MMSE scores ranging from 3-11). The data showed that more than half of the patients, fifty-two percent, were capable of completing the QoL-AD. This finding provides support that IWDs can rate their own QoL with high reliability and validity (Hoe et al., 2005; Logsdon et al., 2002; Selwood et al., 2005). It also provides evidence to support that QoL does not decrease as cognition worsens (Hoe et al., 2005; Selwood et al., 2005). In addition, with these measures, caregiver ratings do not fully substitute for patient ratings (Logsdon, Gibbons, McCurry, & Teri, 2002). In order to enhance QoL, potential predictors and the role that they play should be inspected. The following section will further detail the selective five predictors that will be taken into account during the illness process.

### 1.8 Key Predictors of Well-Being Outcomes

By examining specific key predictors, future interventions will be better capable of addressing the various sources and types of impairment experienced by the IWD (Diwan, Hougham, & Sachs, 2004). There has yet to be sufficient research done using the SPM for IWDs as a conceptual model in regard to key predictors and well-being outcomes. Using this conceptual model has the potential to make treatments more effective. For example, treatments may be more effective if they were able to target patients with higher levels of PADL and/or IADL distress and intervene, rather than treating these patients the same way as patients who experience lower levels of distress (Simard, Hudon, & Van Reekum, 2009). Five specific constructs that can be looked at as predictors and include: level of cognitive impairment, level of PADL experienced, level

of IADL distress experienced, relationship strain, and role captivity. Each of these predictors has the potential to be intervened on if targeted during in the dementia process. Level of cognitive impairment or function may impact the effectiveness that an intervention technique has on the individual (Di Mattei et al., 2009). However, there is not yet a clear consensus on whether or not there is a correlation between the individual's cognitive status and vulnerability to depression, anxiety, and a lower QoL (Di Mattei et al., 2009). Delineating the affect that a patient's level of cognitive impairment has on depression, anxiety, and QoL may provide better insight into the individual's experience.

Distress is generally defined as a reaction to external and internal stressors (Simard, Hudon, & Van Reekum, 2009). It has been found to have relevance to a patient's QoL and even play a role in the prediction of treatment outcome. Experiencing distress is common in dementia patients and can potentially be modified (Wilson, Arnold, Schneider, Li, & Bennett, 2007). This is an important aspect to recognize since proneness to experience distress has been associated with dementia. Possible explanations for this relation have been attributed to distress being a manifestation of the neuropathology hypothesized to contribute to dementia (Wilson, Arnold, Schneider, Li, & Bennett, 2007). There have been few studies that have examined this issue, and therefore, distress that patients experience has been overlooked for a considerable amount of time. This may be mainly because of the fact that PADL and IADL distress could only be accounted for by self-report data from the IWD. More recent studies have found that experienced distress is relevant to compliance, QoL, and even to the prediction of treatment outcome (Simard, Hudon, & Van Reekum, 2009). Wilson et al (2007) conducted a study to examine whether or not common age-related neuropathology was able to account for the

relationship of chronic distress and dementia. Their study concluded that distress is common in IWDs and that a higher level of chronic distress is associated with a higher likelihood of dementia (Wilson, Arnold, Schneider, Li, & Bennett, 2007). In fact, when compared to individuals with a low level of distress, individuals with a high level of distress were twice as likely to have dementia close to death. Distress is an important key predictor to consider since it has been found to play a role in the likelihood of dementia. By addressing the different types of distress, particularly PADL and IADL, interventions could be more focused to enable the targeting of specific predictors. PADL distress and IADL distress experienced should be investigated further in regard to how they impact depression, anxiety, and QoL.

Relationship strain can occur between caregivers and individuals with dementia, and it is clear that dementia has a distinct impact on interpersonal relationships (Ablitt, Jones, & Muers, 2009). A review conducted by Ablitt, Jones, & Muers (2009) examined the impact of dementia on the quality of relationships. The review stated that prior research has found that the quality of the relationship between the caregiver and the IWDs is linked to their experience of living with dementia. Generally, caregivers have reported a decline in the quality of the relationship, specifically in intimacy, reciprocity, and communication. These declines are important to rectify in order to maintain a sense of mutuality between the caregiver and the care receiver (Ablitt, Jones, & Muers, 2009). Being able to recognize whether or not the experienced relationship strain and role captivity have a predicting affect for depression, anxiety, and QoL has the potential to help improve targeted assessments, treatments, and methods.

Prior research has indicated that caregiving relationships can add strain to IWDs

and can reinforce their feelings of helplessness and negativity (Scholey & Woods, 2003). It is important to note these aspects of relationship strain because it has been established as an important determinant of the experience of both the caregiver and the IWD throughout the illness process (Ablitt, Jones, & Muers, 2009). Adding strain to the relationship may moderate whether or not the patient experiences more depression and anxiety, or has a poorer QoL. Scholey and Woods (2003) established that recognizing the deficits in these areas may play a potential role in improving displaced coping strategies. Alleviating emotional stress can help lessen the experienced relationship strain and role captivity.

### 1.9 Current Study

Using the conceptual model of the SPM for IWDs, the current study examined key predictors including: level of cognitive impairment, level of PADL distress experienced, level of IADL distress experiences, relationship strain, and role captivity that impact the psychosocial well-being outcomes of depression, anxiety, and quality of life. The data used were secondary data conducted by a larger study that examined the efficacy of the dyadic intervention "Acquiring New Skills While Enhancing Remaining Strengths" (ANSWERS) (Judge, Yarry, & Orsulic-Jeras, 2009; Judge, Yarry, Looman, & Bass, 2012).

### 1.10 Hypotheses

H1: A significant positive correlation was hypothesized for symptoms of depression and symptoms of anxiety, with higher symptoms of depression related to higher symptoms of

anxiety in individuals with dementia.

H2: A significant negative correlation was hypothesized for higher levels of symptoms of depression and QoL.

H3: A significant negative correlation was hypothesized for higher levels of symptoms of anxiety and QoL.

H4: It was hypothesized that individuals with higher symptoms of depression would have a greater level of cognitive impairment, higher level of PADL and IADL distress, and higher level of relationship strain and role captivity.

H5: It was hypothesized that individuals with higher symptoms of anxiety would have a greater level of cognitive impairment, higher level of PADL and IADL distress, and higher level of relationship strain and role captivity.

H6: It was hypothesized that individuals with a lower QoL would have a greater level of cognitive impairment, higher level of PADL and IADL distress, and higher level of relationship strain and role captivity.

## **CHAPTER II**

### **METHODS**

#### 2.1 Participants

This study utilized secondary data collected as part of the larger Project ANSWERS study and will examine IWD's T1 in-person baseline interviews. Participants were recruited from 16 local social service agencies in Northeast Ohio. Participants qualified for the study if they had a diagnosis of memory impairment, community-dwelling living status, a family CG, and a score of 7 or greater on the Mini-Mental State Examination (Judge, Yarry, & Orsulic-Jeras, 2009).

There were 131 IWDs used in the study. Participants' age ranged from 50-95 years old,  $M = 77.15$ ,  $SD = 9.45$ . The range of the MMSE scores was 12-30,  $M = 22.48$ ,  $SD = 5.84$ . The sample consisted of 55.7% females and 61.8% of IWDs that were married. In the sample, 85.5% of IWDs were Caucasians, and 26.8% were college graduates.



## 2.2 Measures

To examine the illness experience of IWDs, three measures of psychosocial well-being outcomes were used including: depression, anxiety, and QoL. Factor analyses were completed on the measures to ensure that the factor structures were preserved using the current sample. Results indicated that all measures demonstrated good factor structure with the current sample.

The CES-D short version was used to measure symptoms of depression (Radloff, 1977). The CES-D consists of 11-items that measure symptoms of depression. Participants were asked to rate how frequently they experienced each symptom, scoring ranges from 'hardly ever,' 'sometimes,' to 'often.' The depression scale had 11 items in it (How often the IWD: did not feel like eating, felt depressed, felt everything was an effort, slept restlessly, felt happy, felt lonely, felt people were unfriendly, enjoyed life, felt sad, felt people disliked the individual, and were not able to get along with others), and had a reliability of .84.

To assess for anxiety symptoms, the Zung anxiety scale was used (1980). The Zung anxiety scale consists of 6 items that assess symptoms of anxiety. Participants rated each item from 'none of the time,' 'some of the time,' 'good part of the time,' to 'most of the time.' The depression and anxiety scales previously mentioned are standard tools used to assess depression and anxiety symptoms. The anxiety scale had 4 items in it ("I feel more nervous and anxious," "I am afraid for no reason," "I am falling apart," "I am upset easily") with a reliability of 0.76.

To assess for the patient's QoL, the scale that was used was developed by Logsdon, Gibbons, McCurry, & Teri (1999). This scale was specifically designed to

assess the QoL for IWDs. and consists of 12 items that are scored using ‘poor,’ ‘fair,’ ‘good,’ and ‘excellent’ as the response choices. There were 12 items in the QoL scale (items regarded physical health, energy level, mood, living situation, memory, the IWD, the IWDs' marriage, relationship with friends, ability to do chores, ability to do things for fun, financial situation, and life as a whole), and the reliability was .83.

The Mini-Mental State Examination (MMSE) was used to measure level of cognitive impairment of IWDs. The MMSE is a 11-item brief cognitive assessment tool that indicates level of cognitive impairment, ranging from no impairment (scores 24 and above); mild to moderate impairment (score 12-23); and severe impairment (scores 0-11). Cognitive impairment had 8 items in the scale ("I remember events," "I remember the day," "I remember my address," "I use the right words," "I understand instructions", "I find my way in the house," "I speak in full sentences," "I recognize people"), and had a reliability of .73.

Measures of dyad role strain and level of distress were collected using the Dyad Relationship/Role Strain assessment (Zarit, Reever, & Bach-Peterson, (1980) and a newly created assessment tool that examines level of distress experienced by IWDs' in completing functional activities of daily living (Judge et al, 2012). The measure of dyad role strain consist of 12 items that measure relationship and role strain experienced in receiving care due to a chronic illness. Participants were asked to rate each statement using a 4-point Likert scale, from ‘strongly agree,’ ‘agree,’ ‘disagree,’ or ‘strongly disagree.’ Classic role strain had 6 items in the scale ("I feel I'm being manipulated," "I have a strained relationship with caregiver," "I feel resentful," "I feel angry," "I do not feel appreciated," "I do not feel close to caregiver"), and the reliability was .83. Role

Captivity had 3 items in the scale ("I wish I was free to lead my own life," "I feel trapped," "I want to run away"), and the reliability was .82.

The measure of distress consists of 16 items that measure the level of distress experienced in completing personal and instrumental activities of daily living.

Participants were asked to rate each item from 'no difficulty,' 'a little difficulty,' 'a fair amount of difficulty,' to 'very difficult.' IADL distress had 10 items in the scale (items regarded tasks such as writing checks, keeping tax records, shopping alone, playing games/having hobbies, being able to properly turn on/off the stove, meal preparation, current events, paying attention, remembering appointments, traveling), and had a reliability of .88. PADL distress had 6 items in the scale (items regarded tasks such as eating/cutting food, toileting, bathing/showering, dressing/undressing, grooming, getting in/out of the bed or chair), and had a reliability of .83.

### 2.3 Analytic Approach

In regard to hypotheses 1-3, correlation coefficients were used to examine the relationship between variables. For hypotheses 4-6, separate regression models were used to investigate the unique variance contributed by cognitive impairment, PADL distress, IADL distress, relationship strain, and role captivity for each of the following outcomes: depression, anxiety, and QOL.

## CHAPTER III

### RESULTS

#### 3.1 Results

In regard to hypotheses 1 – 3, correlation coefficients were used to examine the relationship between constructs. For hypothesis 1, a significant positive correlation was found between symptoms of depression and symptoms of anxiety ( $r = .55, p = .000$ ), with higher symptoms of depression related to higher symptoms of anxiety.

For hypothesis 2, a significant negative correlation was found between higher levels of symptoms of depression and QoL ( $r = -.66, p = .000$ ), with higher symptoms of depression related to a worse overall QoL.

For hypothesis 3, a significant negative correlation was found for higher levels of symptoms of anxiety and QoL ( $r = .37, p = .000$ ), with higher symptoms of anxiety related to a worse overall QoL.

For hypotheses 4 - 6, separate regression models were used to investigate the unique variance contributed by cognitive impairment, PADL distress, IADL distress,

relationship strain, and role captivity for each of the following outcomes: depression, anxiety, and QOL.

For hypothesis 4, the overall model was found to be significant ( $F_{(5,120)} = 19.36$ ,  $p = .000$ ), accounting for 45% ( $R^2 = .45$ ) of the total variance. Significant unique predictors of symptoms of depression in the model included: PADL distress ( $\beta = .27$ ,  $p = .002$ ), cognitive impairment ( $\beta = .25$ ,  $p = .008$ ), and relationship strain ( $\beta = .17$ ,  $p = .037$ ). Although not statistically significant, IADL distress was approaching significance ( $\beta = .16$ ,  $p = .087$ ). These results indicated individuals with greater distress in PADL, more cognitive impairment, and more relationship strain experienced more symptoms of depression.

For hypothesis 5, the overall model was found to be significant ( $F_{(5,119)} = 14.09$ ,  $p = .000$ ), accounting for 37% ( $R^2 = .37$ ) of the total variance. Significant unique predictors of symptoms of anxiety in the model included: cognitive impairment ( $\beta = .420$ ,  $p = .000$ ). IADL distress, PADL distress, relationship strain, and role captivity were not significant in regards to anxiety symptoms. These results indicated individuals with more cognitive impairment experienced more symptoms of anxiety.

For hypothesis 6, the overall model was found to be significant ( $F_{(5,120)} = 12.02$ ,  $p = .000$ ), accounting for 33% ( $R^2 = .33$ ) of the total variance. Significant unique predictors of QoL in the model included: relationship strain ( $\beta = -.35$ ,  $p = .000$ ), PADL distress ( $\beta = -.27$ ,  $p = .006$ ), and cognitive impairment ( $\beta = -.20$ ,  $p = .055$ ). These results indicated individuals with more relationship strain, greater distress in PADL, and more cognitive impairment experienced decreased overall QoL.

## **CHAPTER IV**

### **DISCUSSION**

The current study addressed numerous gaps in the previous literature. In particular, this study used self-reported measurements from IWDs and used a conceptual model that delineated the illness experience of IWDs. The study also addressed gaps by examining psychosocial outcomes as separate constructs and by investigating key predictors for each outcome. Self-report data from IWDs were used for predictor and outcome measures. These self-reported measurements demonstrated good validity and reliability, supporting the notion that IWDs can rate their own depression symptoms, anxiety symptoms, and QoL.

Results found the key well-being outcomes of depression symptoms, anxiety symptoms, and QoL were significantly correlated with one another. However, additional results indicated unique predictors of each of these outcomes. There has been previous research that has argued that anxiety symptoms and depression symptom should be addressed and treated as a one underlying aspect of the illness experience. This study provides support that these well-being outcomes need to be addressed separately in

understanding the illness experience. Finding that depression symptoms, anxiety symptoms, and QoL are correlated with one another supports research that has found that anxiety and depression have been linked with QoL (Seignourel et al., 2008). It was found that higher symptoms of depression were related to higher symptoms of anxiety. This may be why previous research has had a difficult time delineating the symptoms for each of these two psychosocial outcomes (Seignourel et al., 2008).

A significant negative correlation between symptoms of depression and QoL shows that higher symptoms of depression were related to a worse overall QoL. In addition, the significant negative correlation between symptoms of anxiety and QoL, indicated that higher symptoms of anxiety were related to a worse overall QoL. These findings add support to research that has found that anxiety has had a significant, negative impact on the individuals' functioning, and has been associated with poorer QoL, even when controlling for depression (Paukert et al., 2010). With this knowledge, it is important that future treatment techniques and interventions address anxiety and depression symptoms separately in order to better enhance QoL. Findings also confirm that anxiety in IWDs is significantly associated with more symptoms of depression, worse QoL, and increased cognitive impairment (Seignourel et al., 2008; Ferretti et al., 2001; Paukert et al., 2010).

The SPM for IWDs also delineated key predictors for each of the psychosocial constructs. Results indicated that each of the three constructs had different key predictors. Significant unique predictors of symptoms of depression in the model included: greater PADL distress, greater cognitive impairment, and more relationship strain. Although not statistically significant, IADL distress was approaching significance. The current study

supported the findings that found depressive symptoms can be due to events as straight forward as the loss of mobility or daily living skills (Scholey and Woods, 2003). This confirmation was shown by PADL distress contributing the most unique variance to depression symptoms. By targeting these predictors, potentially, interventions will have a greater impact and be more effective for patients experiencing depression symptoms. For example, future interventions can target PADL distress, cognitive impairment, and relationship strain in order to prevent or lessen depression symptoms for IWDs. Results also support findings that level of cognitive impairment does not solely predict depression in IWDs (Holtzer et al., 2005). This is apparent by the fact that cognitive impairment, as measured by individuals' MMSE score, was not the only significant predictor of depression symptoms.

The only unique predictor for greater symptoms of anxiety was higher level of cognitive impairment. For this reason, it may be beneficial to address these potential symptoms for individuals who show more cognitive impairment in order to prevent the symptoms from occurring. In addition, since cognitive impairment was the only significant predictor for anxiety symptoms, this knowledge could potentially make it easier for interventions to specifically target the anxiety that IWDs feel. It is interesting to note that individuals who had more mild symptoms of dementia did not have as many symptoms of anxiety. This finding is of interest given that individuals with more cognitive impairment most likely have less cognitive resources as related to the role of insight. Therefore, they may be less capable of managing symptoms and experience more anxiety symptoms. More research is needed to see how cognitive impairment affects psychosocial outcomes.



Significant unique predictors of lower QoL were more relationship strain, greater PADL distress, and more cognitive impairment. These findings support prior research that concluded depression and decreased activities of daily living have been found to negatively influence QoL in IWDs (Wetzels, Zuidema, Jonghe, Verhey, & Koopmans, 2010). By attending to the relationship strain between caregivers and IWDs, it is possible that IWDs can experience a better overall quality of life. These results have provided support that even small aspects of life, such as personal activities of daily living, have a large impact on IWDs and need to be addressed in order to improve the illness experience. Furthermore, this information would be helpful in developing interventions. For example, for an individual who has higher symptoms of depression, interventions could be developed to address PADL distress, relationship strain, and cognitive impairment to help alleviate these symptoms. Attending to the predictive factors could potentially be more effective for IWDs.

Based on these findings it is interesting to note the role that cognitive impairment played in all three. Specifically, greater cognitive impairment across all three constructs were related to all three outcomes. This is interesting because individuals with more cognitive impairment may have a greater lack of insight. It may be that individuals with more cognitive impairment are less effective at explicitly managing their feelings, which results in greater anxiety symptoms, depression symptoms, and QoL. This finding also may be of interest given that individuals with less cognitive impairment and subsequently more insight would be more aware and experience anxiety and depression symptoms at a greater rate. However, results of this study indicates that the opposite of this may be true. More research is needed to address this concern regarding cognitive impairment and its

effect on psychosocial outcomes.

Depression symptoms and QoL had the same set of predictors. Therefore, it endorses former findings that depressive symptoms are strongly associated with a negative QoL (Logsdon, Gibbons, McCurry, & Teri, 2002). Prior research has indicated that defining anxiety in IWDs is complicated by the overlap between symptoms of anxiety, depression, and dementia (Seignourel et al., 2008; Ferretti et al., 2001). However, the present study has shown that looking at what key predictors contribute unique variance helps separate these outcomes from one another. It is important to note that role captivity was not found to be a significant unique predictor for depression symptoms, anxiety symptoms, or QoL. For treatment purposes it is important to understand what is predicting the negative symptoms of these outcomes.

Now knowing that these psychosocial outcomes each have a least one specific key predictor, it may be that by attending to and changing the key predictors directly, patients may experience less anxiety or depression, which could cause an overall better QoL. By attending to each psychosocial outcome separately, there is hope to further understand the illness experience of individuals with dementia. Also, by addressing the predictors that provide significant unique variance to each construct, there is great potential to advance and adapt intervention techniques. For example, since it was found that IWDs who have low cognitive impairment experience higher anxiety symptoms, interventions can be aimed to address these patients by targeting the specific predictor.

There are limitations to the current study. On average, the individuals used in this sample had mild-to-moderate cognitive impairments. In order to generalize these results for IWDs, it would be beneficial to utilize a sample with individuals who have moderate-

to-severe cognitive impairments. IWDs with moderate-to-severe cognitive impairments may experience or report different stressors and symptoms, which could change the results of the study. Another limitation of the study is that the individuals in the sample were mainly Caucasian. It is important, moving forward, that samples with different racial backgrounds and ethnicities are used in order to generalize the findings to a wider range of individuals. Individuals with different racial backgrounds and ethnicities may experience separate stressors or symptoms. It also is important to note that cultural differences could affect relationship dynamics, specifically how caregivers and their obligations may vary depending on cultural norms. Lastly, the lack of measures specifically designed for IWDs is another limitation of this study. Even though the measures demonstrated good reliability and validity, further research is needed to develop specific measures for IWDs.

The findings of this study support prior research indicating IWDs are capable of participating in research using standardized measures to examine their illness experience (Hoe et al., 2005, 2007; Logsdon et al., 2002; Selwood et al., 2005). Results demonstrated the use of the SPM for IWDs as a conceptual framework for understanding the illness experience from the individual's perspective. The SPM for IWDs also delineated key predictors for each of the psychosocial constructs. By examining the role of psychological, social, and cognitive predictors, the findings of the current study provided important information regarding the subjective world of dementia and the illness experience of IWDs.

Additional research, however, is needed to investigate how exactly level of cognitive impairment impacts these psychosocial outcomes. Future research should

explore whether or not an IWD's ability to effectively manage and cope with their symptoms plays a key role in outcomes. Further research also is needed to explain the illness experience from the perspective of the IWDs to ensure that interventions are properly targeting relevant well-being outcomes. The knowledge that can be gained by examining previous and current research has the potential to improve and develop future care practices and new intervention techniques.

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