

Predictors of Self-Reported Psychosocial Outcomes in Individuals With Dementia

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Purpose: Little is known about the illness experience from the perspective of individuals with dementia (IWDs), as most quantitative research has focused on IWDs' psychosocial issues from proxy reports. The primary aim of this study was to better understand the impact of the illness experience on well-being from the perspective of the IWD through the framework of the Stress Process Model for Individuals with Dementia (SPM for IWDs). **Design and Methods:** Guided by the SPM for IWDs, self-report data were collected from IWDs ($N = 131$) about their illness experience, including primary objective and subjective stressors, secondary role and intrapsychic strains, and well-being outcomes. Using multiple linear regression, primary stressors, secondary strains, and background and context characteristics were entered into 3 prediction models for each outcome: anxiety, depression, and quality of life (QoL). **Results:** Three distinct prediction patterns emerged for each of the outcome measures. Embarrassment about memory loss was the unique predictor of anxiety, whereas physical health strain and role captivity uniquely predicted depression. Unique predictors for QoL included lower perceived instrumental activities of daily living (IADL) difficulty and higher self-efficacy. **Implications:** This study provided valuable insight into the illness experience from the perspective of the IWD and identified key areas amenable to interventions, such as

managing embarrassment about memory problems as well as improving self-efficacy and inner strength. Moreover, this study provided additional support for the inclusion of IWDs in the research process and highlighted the need for further research regarding clinical application of findings, testing of hypotheses, and analyzing efficacy of interventions.

Key Words: Anxiety, Depression, Quality of life, Stress process model, Illness experience, Dementia

Only recently have researchers begun to explore and understand the illness experience from the perspective of the individual with dementia (IWD; e.g., Harman & Clare, 2006; Hoe, Katona, Orrell, & Livingston, 2007; Hoe, Katona, Roch, & Livingston, 2005; Koppel & Dallos, 2007; Selwood, Thorgrimsen, & Orrell, 2005; Shankner, Walker, Frost, & Orrell, 1999; Snow et al., 2012). Qualitative research studies (Gillies, 2000; Harman & Clare, 2006; Koppel & Dallos, 2007; Menne, Kinney & Morhardt, 2002) have given the IWD a voice through discussing their illness experience subjectively. These studies have validated the feelings and experiences of the IWD while also elucidating key themes expressed by IWDs. Specifically, research has found that IWDs want to understand their illness and maintain their personal identity (Harman & Clare, 2006) and

strive to retain their functional independence through maintenance of driving and completing daily activities (Menne et al., 2002). Recently, Wolverson, Clarke, and Moniz-Cook (2010) found several themes regarding the importance of IWD's maintaining their current level of quality of life (QoL) through relationships, health, and positive coping. Overall, these studies provide a foundation for understanding key aspects of the illness experience of IWDs and have provided the groundwork for further research regarding potential interventions and hypothesis testing using quantitative methods.

However, little is known about the illness experience from the perspective of IWDs using quantitative research methods. The majority of quantitative research has used proxy reports from clinicians or caregivers (CGs) to understand the illness experience of IWDs and key predictors of well-being outcomes. Examples of proxy report measures include the Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian, 1988; Snow et al., 2005) and the Behavioral Pathology in Alzheimer's Disease scale (BEHAVE-AD; Reisberg, Borenstein, Salob, & Ferris, 1987). Although these studies attempted to portray the psychosocial profile of IWDs, potential biases of the informant may lead to over- or underestimations resulting in limited information and conclusions (Snow et al., 2005). For example, CGs consistently rated QoL for IWDs lower than self-reported ratings by IWDs (Arlt et al., 2008). Mixed findings have been found for proxy-reported versus IWD self-reported depressive symptoms. Teri and Wagner (1991) found depressive symptoms were reported at a higher frequency through CG proxy reports than by IWDs themselves. Another study found clinicians' evaluations to be congruent with IWDs' depressive symptoms (Arlt et al., 2008) leaving it unclear whether proxy reports regarding affective well-being measures of IWDs are truly more reliable than self-reports. Although this study does not focus on the comparison between proxy report and self-report, it is important to understand that proxy reports may not accurately reflect the perceptions or subjective feelings and experiences of the IWD, thereby providing misinformation regarding their individual illness experience.

Given the recent findings indicating that IWDs are able to participate in surveys and provide consistent and accurate responses to quantitative questions (Clark, Tucke, & Whitlatch, 2008; Krestar, Looman, Powers, Dawson, & Judge, 2012;

Logsdon, Gibbons, McCurry, & Teri, 2002; Snow et al., 2005), it is important to extend this line of inquiry by examining the illness experience from the perspective of the IWD using self-report data. Specifically, a pivotal question is how IWDs' perceptions along with their subjective feelings and experiences impact their psychosocial well-being, such as anxiety, depression, and QoL. Arlt and colleagues (2008) identified IWDs as important informants regarding their QoL and depressive symptoms. Anxiety, depression, and QoL are useful outcome measures and are often linked to the IWDs' physical and psychological well-being (Ferretti, McCurry, Logsdon, Gibbons, & Teri, 2001; Hoe et al., 2005, 2007; Logsdon et al., 2002; Ownby, Harwood, Barker, & Duara, 2000; Selwood et al., 2005). Gaining insight into the predictors of these psychosocial outcomes from the perspective of the IWD is crucial in understanding the illness experience and identifying areas amenable to interventions.

Stress Process Model for IWDs

Few studies, whether qualitative or quantitative, have used a conceptual model to understand the illness experience of IWDs. To address this need, Judge, Menne, and Whitlatch (2010) adapted Pearlin, Mullan, Semple, and Skaff's (1990) Stress Process Model for CGs to IWDs. The Stress Process Model for Individuals with Dementia (SPM for IWDs) is a conceptual framework used to describe the illness experience of dementia that allows for testing of hypothesized pathways using predetermined psychosocial predictors (Judge, Menne, & Whitlatch, 2010). It includes the following constructs: background and context characteristics (e.g., gender, race), primary objective and subjective stressors (e.g., cognitive/functional status, role captivity), secondary role and intrapsychic strains (e.g., dyad strain, perceived health strain), well-being outcomes (i.e., anxiety, depression, QoL), and internal and external mediators (e.g., personality, social support). See Figure 1 for representation of SPM for IWDs. *Background and context characteristics* take into account an individual's life circumstances. These characteristics represent a person's current environment or situation (i.e., living arrangement or relationship with CG) or a lifelong attribute (e.g., race, gender). *Primary stressors* account for the amount and type of impairment experienced by the IWD and can be divided into subjective and objective indicators. Objective primary stressors

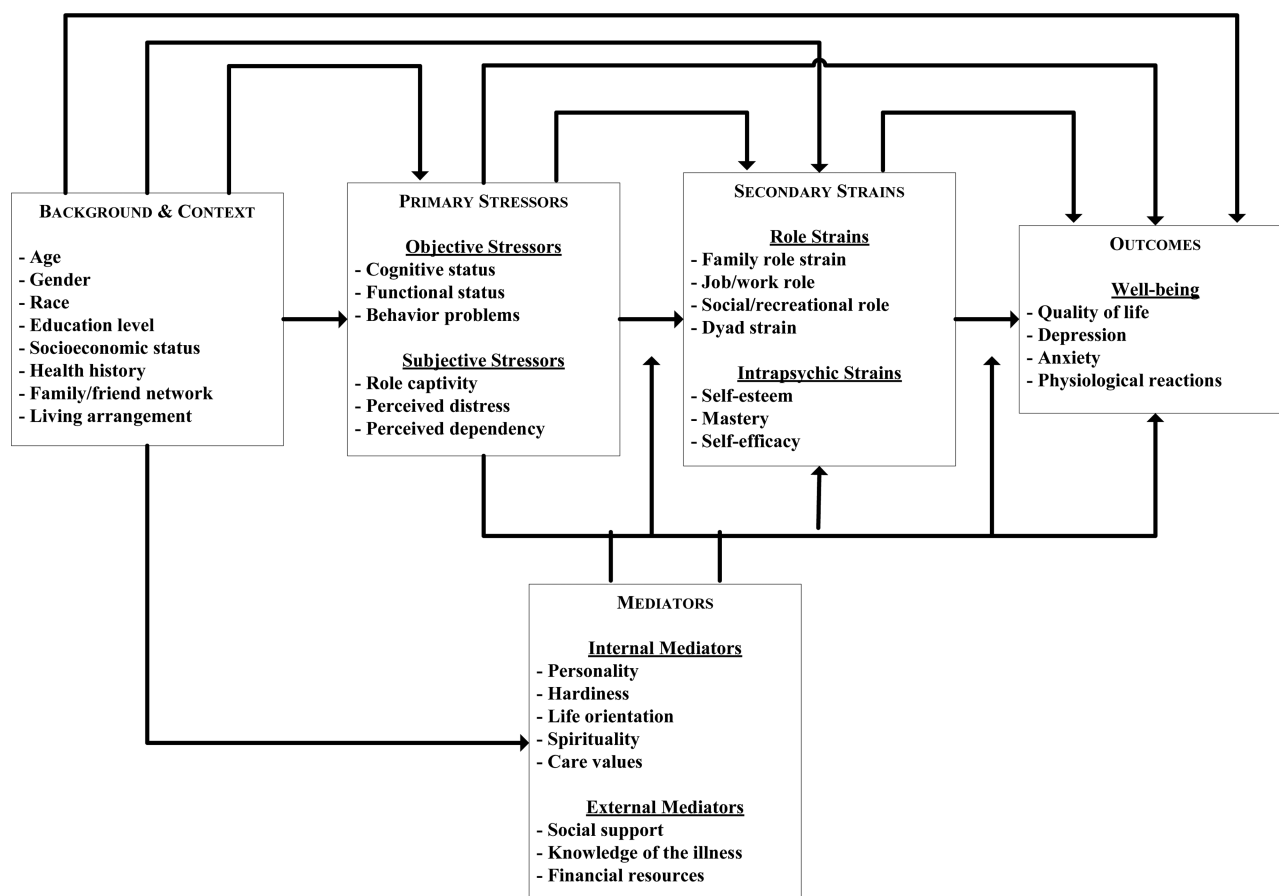


Figure 1. Stress process model for individuals with dementia (IWDs; Judge, Menne, and Whitlatch, 2010).

describe the type and severity of one's primary dementia symptoms, such as cognitive symptoms or functional difficulties. Subjective primary stressors are the emotional and psychological consequences resulting from the cognitive, functional, or behavioral aspects of the dementia, such as perceived distress or role captivity. *Secondary strains*, which are additional sources of stress resulting from the primary stressors, can be described as either role strains or intrapsychic strains. Role strains comprise life roles that are affected by living with dementia and include family/dyadic roles or work roles. These secondary strains also can manifest internally through intrapsychic strains, such as perceived health strain or embarrassment about one's memory problems (Judge, Menne, and Whitlatch, 2010).

Internal and external *mediators* may affect several pathways in the conceptual framework. Different mechanisms for coping, personality traits, and external resources may buffer or modify how an IWD manages the illness experience. The SPM for IWDs includes measures of well-being in the construct of *outcomes* including anxiety, depression, and QoL. Conceptually, these outcomes are

the net result of the various constructs outlined in the SPM for IWDs and are indicators of an individual's overall physical, psychological, and emotional well-being (Judge, Menne, and Whitlatch, 2010). As outlined in the next sections, recent literature has delineated each of these psychosocial outcomes in IWDs; however, no study to date has compared how the same stressors differentially affect well-being.

Anxiety

Anxiety is an area of emerging concern in the study of IWDs, as the prevalence rates vary between 38% to as high as 72% (Ballard et al., 2000). Symptoms of anxiety are associated with lower QoL, more functional limitations, poorer physical health, reduced activities, and more behavioral disturbances, even when controlled for depression. Correlations between anxiety and QoL have been found to range from $-.30$ to $-.64$ (Seignourel, Kunik, Snow, Wilson, & Stanley, 2008). Higher anxiety has been found to be related to increased nursing home placement (Seignourel et al., 2008).

Assessment tools used to detect anxiety in IWDs are generally accepted as reliable, although

their validity has come into question as anxiety and depression are found to be highly correlated. Some researchers have argued that anxiety and depression should not be separated into distinct constructs (Seignourel et al., 2008). Two studies (Ferretti et al., 2001; Ownby et al., 2000) investigated predictors of anxiety in IWDs, however, both used informant-based anxiety measures as the outcome variable, which, as discussed earlier, can be problematic. Ferretti and colleagues (2001) used the Revised Memory and Behavior Problems Checklist (RMBPC) via CG proxy reports to measure IWD's anxiety. The best predictors of anxiety were disruptive behaviors (e.g., arguing, verbal aggression, waking CG at night), increased memory impairment, depression, and hallucinations. These predictors were different from those identified by Ownby and colleagues (2000) whose only similar predictor was activity disturbances (e.g., wandering, purposeless activity). Both studies found that disturbances (as reported by CGs) predicted IWD's anxiety, whereas only one found that cognitive status was not significant (Ownby et al., 2000). Although the sample used in the Ownby study was somewhat older (80.2 vs. 73.6 years old), both samples exhibited similar levels of cognitive impairment as measured by the Mini-Mental State Examination (MMSE; 16.7 vs. 16.2).

It is important for researchers to use assessment tools that allow the IWD to report their own feelings and symptoms as many of the core symptoms of anxiety, such as worrying or difficulty controlling worry, are private in nature and might not be known to the CG. Moreover, proxy reporters may mistake some IWDs' behaviors, such as restlessness or fidgeting, as symptoms of anxiety (Seignourel et al., 2008). Therefore, it is important to gather a first-hand account of feelings and symptoms from the IWD as to not confound any biases from the informant or confuse signals of concomitant behaviors as symptoms of anxiety. To date, only one such scale exists that has been specifically developed for IWDs. The Rating for Anxiety in Dementia (RAID; Shankner et al., 1999; Snow et al., 2012) assesses symptoms of anxiety in IWDs and enables individuals to express feelings of worry, apprehension, and tension. Additionally, this measure also incorporates a CG proxy component. Collectively, this scale gives researchers and clinicians a global rating of the IWDs' anxiety.

In a critical review, Seignourel and colleagues (2008) found anxiety symptoms not to be generally

related to gender, education, or age. Anxiety was found to be relatively stable across the range of dementia severity until the terminal stages where it decreased, suggesting that cognitive status does not relate to levels of anxiety except at the most severe stages. Other studies have found mixed empirical evidence. For example, Ownby and colleagues (2000) did not find that cognitive impairment predicted higher levels of proxy-reported anxiety, whereas Ferretti and colleagues (2001) concluded that cognitive status predicted significantly higher levels of proxy-reported anxiety in IWDs.

Depression

Depression has been associated with increased functional disability in the elderly population (Greenglass, Fiksenbaum, & Eaton, 2006) and linked to immunosuppression and increased risk for chronic illness (Berg, Smith, Henry, & Pearce, 2007). Clinical and even subclinical levels of depressive symptoms have been found to be strong predictors of morbidity and mortality in older adults (Gruenewald & Kemeny, 2007).

Snow and colleagues (2005) found that IWDs with lower awareness of deficits reported lower levels of depressive symptoms than IWDs with more insight. Similar to these findings, higher levels of depression were found early in the illness and steadily declined as the disease progressed (Holtzer et al., 2005). In this same study, increases in depressive symptoms were not linked with cognitive decline but with functional decline over a 5-year period, indicating that depressive symptoms were linked to functional activities, such as activities of daily living (Holtzer et al., 2005).

As with anxiety, the vast majority of current literature relies on proxy reports or clinician observations to measure depressive symptoms in IWDs. Many depressive symptoms, such as feeling sad or lonely, are also private and internalized and may be unknown to the CG, whereas other symptoms, such as fatigue or decreased appetite, may be mistaken as depressive symptoms when in fact they are symptoms of another cause (e.g., infection). However, proxy reports continue to be used even though researchers have found that presence of dementia does not predict inaccurate depression self-reports (Snow et al., 2005) and IWDs are able to respond consistently to self-report questions (Clark et al., 2008) regarding these internalized perceptions and subjective feelings.

Quality of Life

QoL, a subjective global rating of physical, psychological, and social well-being, is a commonly used psychosocial outcome measure in quantitative research and can be used to determine the efficacy of psychosocial interventions (Logsdon et al., 2002). Research has found that individuals with mild-to-severe dementia are able to rate their QoL using standardized measures such as the Quality of Life in Alzheimer's Disease (QoL-AD) (Hoe et al., 2005, 2007; Selwood et al., 2005).

Hoe and colleagues (2005, 2006, 2007) provide consistent examples of using standardized self-report QoL measures with IWDs who have varying cognitive symptoms (i.e., mild to moderate to severe) in the London and South East Region of the U.K. (LASER-AD) study. In 2005, the authors collected information from 79 participants with severe dementia (MMSE scores of 3–11). Fifty-two percent of IWDs were able to complete the QOL-AD, providing evidence for validity and reliability of the QOL-AD with severely impaired individuals. Another study by Hoe, Hancock, Livingston, & Orrell (2006) examined the QoL of IWDs in residential care homes, demonstrating the use of standardized measurement tools in an institutional setting giving IWDs a voice regarding their illness experience (Hoe et al., 2006). Finally, in 2007, Hoe and colleagues measured QoL in a group of moderately to severely impaired IWDs taking acetylcholinesterase inhibitors (AChEI) finding those IWDs taking AChEI medication had higher overall rated QoL.

QoL has been found to correlate negatively with both depression ($r = -.47$) and anxiety ($r = -.75$; Selwood et al., 2005), whereas having no relationship to cognitive status (Hoe et al., 2005; Selwood et al., 2005). In general, these findings dispute common assumptions that worsening dementia leads directly to a lower QoL for the IWD (Hoe et al., 2005, 2007; Selwood et al., 2005).

More research is needed to better understand and describe the illness experience from the perspective of the IWD. Furthermore, findings from self-report data could be used to develop efficacious interventions targeted at reducing negative symptoms associated with dementia. Significant gaps in the literature exist using IWD self-reports as predictor and/or outcome variables, as it has been shown that using only proxy reports may lead to over- or underestimation of an IWD's perceptions and/or symptoms. There is a dearth of

research including multiple constructs designated to measure physical and psychological well-being. Therefore, it is vital to measure these constructs simultaneously in order to better understand the complex relationships between potentially confounding variables.

The primary aim of this study was to better understand the impact of the illness experience on well-being from the perspective of the IWD using the SPM for IWDs. To do so, three specific self-reported well-being outcome measures were modeled: anxiety, depression, and QoL. Due to the availability of all three outcome measures, we were able to statistically control for high levels of correlation among the outcome variables in order to better understand the relationship among these measures.

Design and Methods

Participants

The sample consisted of 131 IWDs who were part of a larger randomized controlled trial funded by the National Institute on Aging and the Alzheimer's Association implementing a dyadic intervention for IWDs and their CGs. (For a complete description of the recruitment and sampling methods for this project, see Judge, Yarry, and Orsulic-Jeras, [2010]; Judge, Yarry, Looman, & Bass [2012].) 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 MMSE (Folstein, Folstein, & McHugh, 1975). Participant demographics are summarized in Table 1.

Procedure

Guided by the SPM for IWDs (Judge, Menne, and Whitlatch, 2010), participants completed an in-person interview about their illness experience. Data for this study came from the first of two in-person interviews conducted approximately 15 weeks apart. Interviews were conducted by experienced interviewers trained in techniques aimed at enhancing the ability of older persons with memory loss to provide responses. Response cards containing the response choices in large font sizes on high-contrast backgrounds were handed to respondents at appropriate points during the interview to assist them with their selection of answers to questions. Each time a new response scale was

Table 1. Sociodemographic Characteristics of Respondents (N = 131)

Respondent characteristics	Mean	SD
Age (range = 50–95 years)	77.15	9.45
MMSE score (range = 12–30)	22.48	5.84
	%	
Female	55.7	
Married	61.8	
Caucasian	85.5	
College graduate	26.8	

Notes. MMSE = Mini-Mental State Examination. For MMSE, higher scores indicate higher levels of functioning. For respondent characteristics reported as percentages, 1 = yes.

presented to participants, interviewers asked the questions with the expectation that respondents would use the full range of responses listed on the response cards (e.g., “no difficulty,” “a little difficult,” “a fair amount,” or “very difficult”). If, after several prompts, respondents were unable to provide a response, interviewers presented the simplified, dichotomous response choices (i.e., “no/yes”) on another card.

Measures

The MMSE was used to assess overall cognitive status, ranging in score from 0 to 30. Lower scores indicate greater cognitive impairment, whereas a score of less than 24 is indicative of cognitive impairment (Folstein et al., 1975).

The following scales were selected based on the SPM for IWDs. To gather information regarding *primary objective and subjective stressors*, the following scales were used: difficulties in completing personal and instrumental activities of daily living (IADL; Benjamin Rose Institute, 1992; Cleveland Alzheimer’s Managed Care Demonstration, 1998; Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; Lawton & Brody, 1969) and role captivity (Bass, Tausig, & Noelker, 1989; Zarit, Reever, & Bach-Peterson, 1980). The following scales were administered to capture *secondary role and intrapsychic strains*: health strain (Bass, Noelker, & Rechlin, 1996), relationship strain (Bass et al., 1989; Zarit et al., 1980), embarrassment about memory problems (Bass et al., 1989; Clark, Bass, Looman, McCarthy, & Eckert, 2004), and self-efficacy learning (Pearlin et al., 1990; modified). *Outcomes* were assessed by anxiety (Zung, 1980), depression (Radloff, 1977), and QoL-AD (Logsdon, Gibbons, McCurry, & Teri, 1999).

Factor analyses were completed on the above scales to ensure that the intended factor structures were maintained using the current sample, as many of the scales were not designed specifically for use with IWDs. Ideally, measures specifically designed for IWDs would have been preferred, but to date, few instruments exist and one of the goals of the larger study was to use parallel measures with both IWDs and their family CGs in order to conduct dyadic analyses examining the joint impact of the intervention protocol. All items demonstrated structural validity and loaded onto the respective subscales at 0.40 or higher (Floyd & Widaman, 1995; Tabachnick & Fidell, 2007, p. 649). Internal consistency of the scales was tested using Cronbach’s alpha. Items were deleted to increase internal consistency as indicated. Specifically, two items from the anxiety scale (“I felt that everything was alright” and “I felt calm”) were removed. All scales used in the analysis demonstrated adequate to good reliability with this sample, with Cronbach’s alphas ranging from 0.64 to 0.81. Table 2 identifies scales included in analyses corresponding to appropriate constructs within the SPM for IWD along with number of items in each scale, Cronbach’s alphas, scale mean, and possible range scores. Final scales used in the regression analyses are outlined in [Supplementary Material](#).

CGs answered questions regarding disruptive behaviors exhibited by the IWD (Bass, McClendon, Deimling, & Mukherjee, 1994; Golden, Teresi, & Gurland, 1984). This 14-item scale, with responses of “sometimes,” “often,” or “most of the time,” demonstrated good reliability with Cronbach’s alpha of 0.75 and included questions regarding difficult behaviors.

Statistical Analyses

Some participants were able to use the full range of responses, whereas other participants required simplified structure. For the purposes of this study’s analyses, all self-report responses were dichotomized into “yes/no,” “agree/disagree,” or “good/bad” answers. For a more in-depth review of participants’ use of response ranges, please see Krestar and colleagues (2012).

Regression Analysis

To better understand the factors that predict psychosocial outcomes in IWDs, three multiple

Table 2. Psychometric Properties of Self-Report Scales Identified Within the Stress Process Model for Individuals with Dementia (SPM for IWDs)

SPM for IWD construct scale	Items in scale	α	Scale score range	Scale mean	SD
Primary objective stressors					
Difficulty with IADL	10	0.76	0–10	3.42 ^a	2.61
Primary subjective stressors					
Role captivity	3	0.64	0–3	0.72 ^b	0.98
Secondary role strains					
Relationship strain (dyad)	6	0.81	0–6	1.10 ^b	1.66
Secondary intrapsychic strains					
Self-efficacy perception (inner strength/growth)	4	0.72	0–4	2.90 ^a	1.27
Health strain (physical)	4	0.75	0–4	0.93 ^b	1.24
Embarrassment about memory problems	7	0.77	0–7	2.20 ^b	2.04
Outcomes					
Anxiety	4	0.72	0–4	1.03 ^a	1.27
Depression	11	0.76	0–11	4.34 ^a	2.41
Quality of life	12	0.69	0–12	11.1 ^c	1.74

Notes: IADL = instrumental activities of daily living

^a0 = no, 1 = yes.

^b0 = disagree, 1 = agree.

^c0 = bad, 1 = good.

linear regression models were used, one to predict each of the outcomes: anxiety, depression, and QoL. After interpreting the bivariate correlation matrices between the outcome variables, demographic information, and scale scores, the same single set of variables (defined subsequently) was entered into each model as a single step as outlined by the SPM for IWDs.

To represent background and context characteristics, the following variables were entered into the model: *race* (White vs. non-White), *education*, *CG/care receiver (CR) relationship* (spouse vs. nonspouse), and *gender*, whereas the following variables were entered to represent primary stressors: *role captivity*, *difficulty with IADLs*, *MMSE score*, and *CG reports of problem behaviors*, and the following variables were entered to represent secondary strains: *physical health strain*, *dyadic relationship strain*, *embarrassment about memory problems*, and *self-efficacy perception*. All variables were entered simultaneously to allow the regression analysis to identify significant and unique predictors of each of the outcomes (anxiety, depression, and QoL).

Anxiety, depression, and QoL outcome measures were added to each model to statistically control for the significant correlations found between these three constructs. This approach enabled a direct comparison of each of the outcome measures by using the same set of predictor variables and covariates. The bivariate correlations between these outcome measures (ranging from -0.13 to 0.61) are

outlined in Table 3, indicating a significant positive correlation between anxiety and depression and a significant negative correlation between anxiety and QoL. Two additional diagnostic analyses, collinearity diagnostics and power analysis, were completed prior to interpretation of the results. Due to the potential higher levels of relatedness between the outcomes variables, the authors wanted to ensure that multicollinearity was not present. Specifically, multicollinearity between variables may inflate the size of the error terms, which could weaken the analysis by making it more difficult to reject the null hypothesis (Bobko, 2001, p. 196). Subsequently, variables with bivariate correlations of greater than .70 should only be cautiously entered into the same analysis (Tabachnick & Fidell, 2007, p. 90) as these variables may be found to have multicollinearity.

To examine this issue, collinearity analysis was completed using SPSS 18.0 software by calculating the variance inflation factors (VIF) values for each regression coefficient to ensure that multicollinearity did not skew the findings. Morrow-Howell (1994) summarizes that VIF values less than 10.0 indicate that multicollinearity is not present, whereas most conservative VIF values of less than 4.0 also have been used. Collinearity diagnostics based on the regression models presented subsequently indicated that multicollinearity was not present for any of the analyses. The highest bivariate correlation between variables was identified at $r = .62$ (depression and physical health strain),

Table 3. Bivariate Correlations Between the Outcomes Measures: Anxiety, Depression, and Quality of Life (QoL)

	Anxiety	Depression	QoL
Anxiety	—	.61**	-.32**
Depression	—	—	-.13
QoL	—	—	—

Note: ** $p < .01$.

which is less than .70 (Tabachnick & Fidell, 2007, p. 90). Additionally, VIF values in the regression equations ranged between 1.08 and 2.27, which is well below the conservative VIF of 4.0 in guarding against multicollinearity.

Due to the number of independent and control variables used in the regression analyses, a calculation of power (Cohen & Cohen, 1975) also was completed to ensure that the sample size and effect size were adequate in this study to identify significant unique predictors in each regression analysis. A conservative effect size of 0.20 was used to calculate the power of an individual regression coefficient because the smallest significant standardized coefficient was 0.22. Based on the regression analyses presented subsequently, adequate power was observed in these analyses as well. Using an effect size of 0.20 and a significance level of 0.05, a power of 0.87 was calculated for the current predictions (Cohen & Cohen, 1975).

Results

Anxiety

Overall, the set of variables entered into the regression equation, including depression and QoL, significantly predicted anxiety ($R^2 = .57$, $F(14,99) = 9.51$, $p < .001$), accounting for 57% of the total variance. Regression coefficients can be found in Table 4. Embarrassment about memory problems was found to significantly predict anxiety, above and beyond the other variables ($\beta = 0.22$, $p = .022$) indicating that IWDs with more embarrassment about their memory problems had more symptoms of anxiety.

Depression

The set of variables representing the SPM for IWDs also significantly predicted depression ($R^2 = .56$, $F(14,99) = 9.03$, $p < .001$), accounting for 56% of the total variance. Physical health strain ($\beta = 0.36$, $p < .001$) and role captivity ($\beta = 0.23$, $p < .01$) were found to be unique and significant

predictors of depression. Results indicated that IWDs with higher feelings of physical health strain and higher perceptions of role captivity were associated with more depressive symptoms.

Quality of Life

Finally, the set of independent variables also significantly predicted QoL ($R^2 = .43$, $F(14,99) = 5.23$, $p < .001$), accounting for 43% of the total variance. Significant and unique predictors of QoL included self-efficacy perception ($\beta = 0.30$, $p < .001$) and perceived difficulty with IADLs ($\beta = -0.28$, $p = .004$). Findings indicated IWDs who perceived less difficulty with IADLs and reported a higher level of inner strength and personal growth demonstrated higher levels of self-reported QoL.

Summary of Results

The set of variables representing the SPM for IWDs significantly predicted each of the outcome variables of anxiety, depression, and QoL with an explained variance of 57%, 56%, 43%, respectively. Because each of the regression equations were significant at less than 0.001, there was a low probability of committing a type I error in this case (Bobko, 2001, p. 199). Of primary interest was whether distinct predictors would emerge while controlling for the other well-being measures (i.e., anxiety, depression, and QoL). Results found separate predictive models for each outcome measure. The sole unique predictor of anxiety was embarrassment about memory problems, whereas physical health strain and role captivity were unique predictors of depression. Finally, QoL was predicted uniquely by self-efficacy perception and perceived difficulty with IADLs.

Discussion

This study addressed several gaps in the literature. Specifically, self-reported measurements from IWDs demonstrated structural validity and good reliability and were used as predictor and outcome variables. By concomitantly measuring and statistically controlling for the three interrelated variables, potential over- or underestimation biases that may exist from using proxy reports were addressed. As a result, distinct models emerged for each outcome.

Anxiety was associated with feelings of embarrassment about one's memory problems, indicating

Table 4. Regression Predicting Three Self-Reported Psychosocial Outcomes of Stress Process Model for Individuals with Dementia (SPM for IWDs)

SPM for IWD construct Variables	Anxiety		Depression		Quality of life	
	SE_B	β	SE_B	β	SE_B	β
Background and context						
Race	0.29	-0.11	0.48	-0.13	0.34	0.14
Education	0.10	0.02	0.18	-0.10	0.11	-0.05
CG/CR relationship	0.26	0.07	1.08	-0.10	0.31	0.09
Gender	0.26	0.12	0.48	-0.13	0.30	0.06
Primary stressors						
Relationship strain: role captivity	0.11	0.10	0.20	0.23***	0.13	0.06
Difficulty with IADL's	0.04	0.06	0.08	0.05	0.05	-0.28***
CG reported behavior	0.02	-0.05	0.04	-0.04	0.02	-0.10
MMSE	0.02	0.01	0.03	0.11	0.02	-0.01
Secondary strain						
Health strain: physical	0.10	0.09	0.17	0.36****	0.11	0.01
Relationship strain: dyad	0.06	0.14	0.12	-0.06	0.07	-0.11
Embarrassment about memory problems	0.06	0.22**	0.11	0.06	0.07	-0.17
Self-efficacy perception: inner strength/ growth	0.08	0.07	0.15	0.02	0.08	0.30****
Controls						
Depression	0.05	0.22**	—	—	0.004	0.06
Anxiety	—	—	0.19	0.22**	0.12	-0.21**
QoL	0.09	-0.16**	0.17	0.003	—	—
F	9.51****		9.03****		5.22****	
R^2	.57		.56		.43	

Notes: IADL = instrumental activities of daily living; MMSE = Mini-Mental State Examination; CG = caregiver.

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

IWDs who reported higher levels of anxiety may be more concerned about what others may think about their deficits. As supported by previous literature (Ownby et al., 2000; Seignourel et al., 2008), an individual's MMSE score was not a significant predictor of self-reported anxiety. Contradictory to prior studies (Ferretti et al., 2001; Ownby et al., 2000), CG reported behaviors were not found to be a predictor of IWDs' anxiety. This difference in this study's findings and prior literature may reflect some of the aforementioned biases present in CG reports.

Depressive symptoms were related to feelings of physical health strain and role captivity brought on by one's cognitive limitations. These beliefs may lead to feelings of dependence or helplessness as physical health strain may be characterized by having less energy, whereas role captivity encompasses feeling "trapped having to depend on CG" (Moos, 1974; Zarit et al., 1980). Our results support findings that cognitive status alone does not predict depression in IWDs (Holtzer et al., 2005), as MMSE was not a significant predictor of depression.

Finally, QoL was significantly linked to self-efficacy and perceived difficulty with IADLs.

Higher levels of QoL were described when greater levels of inner strength were reported along with lower perceptions of difficulty with IADLs, such as managing the finances or practicing a hobby. These findings may indicate that IWDs want to stay involved in IADLs, and it is important that they feel as though they are successful in these tasks. These results mirror many of the themes that have been identified in the rich body of qualitative literature (e.g., Harman & Clare, 2006; Menne et al., 2002).

This study allowed researchers to gain valuable insight into the illness experience from the perspective of the IWD, rather than relying on proxy reports from CGs, along with identified areas that may be amenable to interventions. For example, intervention programs that target management of embarrassment regarding memory problems and self-efficacy may reduce symptoms of anxiety and improve QoL, respectively, in IWDs. One such example is the Peaceful Mind Program (Paukert et al., 2010; Stanley et al., 2012), which is a cognitive-behavioral intervention aimed at reducing the symptoms of anxiety in IWDs. Specifically, this program uses self-monitoring techniques and coping

strategies to alleviate anxiety symptoms. This type of program could be very instrumental in addressing other anxiety-related symptoms such as embarrassment about memory loss, such as forgetting a friend's name or appointment. Although still in the pilot testing phase, the Peaceful Mind Program has demonstrated feasibility and promising efficacy (Paukert et al., 2010; Stanley et al., 2012).

Another potential avenue of intervention includes programs designed to improve physical health strain and role captivity that may reduce symptoms of depression. Higher levels of inner strength and growth, which was shown in our sample to be associated with higher levels of self-reported QoL, could be intervened upon using a strength-based approach (Judge, Yarry, and Orsulic-Jeras, 2010) by allowing IWDs to focus on remaining strengths instead of dwelling on deficits or weaknesses. This may lead to higher levels of self-efficacy and self-confidence. Certainly, more research is needed to further explore these ideas in order to assess the possibility of single or multiple component interventions to improve the psychological, social, and emotional well-being of IWDs.

The findings of this study support prior research indicating IWDs are able to and should participate in survey research using standardized measures to examine the illness experience (Clark et al., 2008; Hoe et al., 2005, 2007; Krestar et al., 2012; Logsdon et al., 2002; Selwood et al., 2005; Snow et al., 2005). It demonstrated the use of the SPM for IWDs as a conceptual framework for understanding IWDs' illness experience from their perspective while delineating key predictive relationships among constructs (i.e., primary objective stressors, secondary role and intrapsychic strain, and well-being outcomes). Specifically, different portions of the SPM for IWDs were represented in unique prediction patterns. Secondary role and intrapsychic strains were represented when uniquely predicting anxiety, whereas both primary subjective stressors and secondary intrapsychic strains uniquely predicted depression symptoms. QoL was best predicted by primary objective stressors as well as secondary intrapsychic strains. Being that the SPM for IWDs incorporates multiple domains and constructs, these findings highlight the usefulness of such a model in describing the illness experience of IWDs. However, more research is needed to determine whether temporal or causal relationships exist between these constructs, as this study provides a solid foundation for future exploration but does not address temporal or causal relationships.

Previous studies have had difficulties disentangling the high intercorrelations between psychosocial outcomes, leading to difficulty in interpreting results. Some researchers argue that anxiety and depression should be treated as a single construct. An advantage of this study was the ability to include each of the well-being outcomes (i.e., anxiety, depression, and QoL) as covariates in the regression equations thereby statistically controlling for the high intercorrelations. These findings lend support to the notion that anxiety and depression are different constructs. More research is required to support or refute this argument, including a larger and more diverse sample of IWDs (i.e., geographic regions, socioeconomic status, ethnicity, more impaired cognition). However, the current findings serve as a starting point for assisting researchers and clinicians in studying or treating symptoms of anxiety and depression, respectively.

Limitations and Future Research Directions

Several limitations of this study should be noted when reviewing the results. First, the sample utilized in this study included individuals with, on average, mild-to-moderate cognitive impairments. It would be important to identify whether these prediction patterns generalize to a more impaired sample, as individuals with more impairments may report different stressors and affective symptoms leading to different outcomes.

Second, participants were recruited from one area (i.e., Cleveland and Akron, Ohio regions) and included individuals with higher levels of education, limiting the ability to generalize these findings to samples with different backgrounds and demographics. Finally, our sample of community-dwelling older adults did not include a variety of racial or ethnic backgrounds. It would be very useful and important for future studies to incorporate individuals from diverse backgrounds, such as socioeconomic or education levels as well as different ethnic or racial backgrounds. For example, there may be differences in perceived difficulties and distresses due to cognitive impairment. Racial and cultural differences in dyadic relationship dynamics also may be studied with a more varied sample of IWDs.

Another limitation of this study is the lack of measures specifically designed for IWDs. Because this project was part of a larger study and few such measures existed at the time of the study, many of the self-report tools used were adapted from CG

measures. Although these measures demonstrated solid reliability and validity via psychometric testing, further research is needed to develop IWD-specific measures that directly assess their illness experience, such as the QOL-AD (Logsdon et al., 1999) and RAID (Shankner et al., 1999; Snow et al., 2012).

Further statistical analysis including structural equation modeling should be completed to test direct and indirect pathways of the SPM for IWDs. As mentioned previously, identifying temporal flow or causal relationships would be important to determine areas most important to interventions. The cross-sectional nature of this study does not allow these relationships to be determined, however, the results provide a solid foundation to indicate the existence of these relationships. Another important area of research should examine the role of mediators (e.g., personality, social support, and spiritual beliefs) and measures of well-being in IWDs as posited by the SPM for IWDs. This information could be used for identifying additional areas amenable to interventions and used to evaluate the efficacy of interventions. The concept of insight into deficits has been addressed in the literature as a potentially important variable in understanding the illness experience (Seignourel et al., 2008). Further research should examine the possible moderating effect that insight into deficits may have on these psychosocial outcomes.

A final area of study is comparing prediction patterns of these psychosocial outcomes in IWDs with those of other chronic illnesses, such as cancer, HIV/AIDS, or arthritis. Literature reveals that CG burden is more severe when caring for an IWD, demonstrating the need for unique interventions for CGs of IWDs (Fortinsky, Tennen, Frank, & Affleck, 2007, p. 235). The same may be asked when developing interventions for IWDs. Specifically, is the illness experience of IWDs similar to the illness experience of other individuals with different chronic health conditions and would similar intervention programs work for different chronic health care conditions.

Supplementary Material

Supplementary material can be found at: <http://gerontologist.oxfordjournals.org>.

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