Decision-Making Involvement of Individuals With Dementia

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Purpose: Research underscores how autonomy and decision-making involvement may help to enhance the quality of life of older adults; however, individuals with dementia are often excluded from decision making that is related to their daily functioning. In this study we use a modified version of the Stress Process Model to consider the stress process of individuals with chronic illness, and in particular to explore the predictors of decision-making involvement among individuals with dementia (n = 215). **Design and Methods:** We collected data from individual with dementia (IWD)–family caregiver dyads. Relying primarily on data from the IWD, we used hierarchical multiple regression analysis to determine the predictors of the IWD's decision-making involvement. **Results:** Results indicate that individuals who report more decision-making involvement are younger, female, have more education, have a nonspousal caregiver, have fewer months since their diagnosis, exhibit fewer problems with activities of daily living and fewer depressive symptoms (based on caregiver report), and place more importance on autonomy/self-identity. **Implications:** In our discussion we examine the importance of autonomy and impairment levels for understanding the decision-making involvement of persons with dementia.

Key Words: Autonomy, Daily functioning, Impairment, Stress process, Well-being

Approximately 24 million people in the world have dementia, and the leading cause of dementia is Alzheimer's disease (Alzheimer's Disease International, 2006). In the United States it is estimated that 4.5 million people have Alzheimer's disease, and that the number of people with dementia is increasing (Alzheimer's Association, 2005). As the prevalence of dementia increases nationally and internationally, social science research on individuals with the diagnosis of dementia (from here on referred to as IWDs) has also expanded. When social research about Alzheimer's disease and dementia flourished in the 1980s, practical difficulties were sometimes encountered that precluded involving IWDs in social science research. Some researchers argued that these individuals were unable to provide meaningful or reliable responses to quantitative research questions (Albert et al., 2001; Kerner, Patterson, Grant, & Kaplan, 1998). At the same time, there was a growing body of qualitative research and anecdotal evidence that noted IWDs' ability to share insights and make decisions about how to live their lives (Davis, 1989; McGowin, 1993; Menne, Kinney, & Morhardt, 2002; Sabat & Collins, 1999). These differing opinions on the ability of IWDs to be involved in research and in their own care planning remain a matter of debate. In addition, writings about quality of life suggest that the autonomy and decision-making preferences of frail older adults are important factors when it comes to understanding an individual's quality of life (Lawton, 1991; Wetle, 1991).

One area of research that examines the involvement of IWDs in making decisions concerns advanced directives and whether or not an IWD chooses to participate in medical treatments (Hirschman, Joyce, James, Xie, & Karlawish, 2005; Karlawish, Casarett, & James, 2002). Hirschman and colleagues noted that "nearly all patients wanted to participate in the decision to take the medicine" (p. 385), and because there was no variance in the patients' desire to participate, all of the analyses conducted for the study were based on caregivers' answers as to whether the IWD would be involved. Based on the caregivers' perceptions of whether an IWD would be involved in deciding to participate in a medical
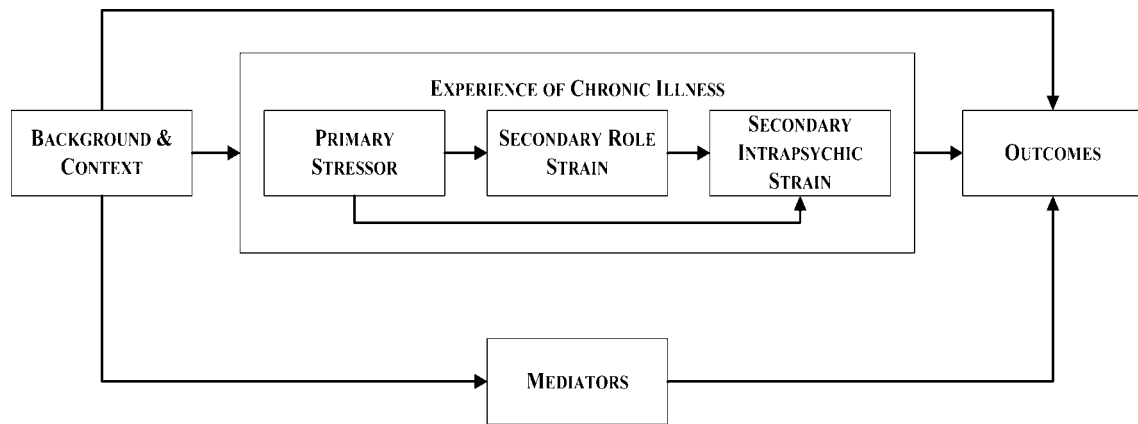
Figure 1. Stress Process Model of Chronic Illness.

treatment, the results point to IWDs' insight and dementia severity as the determining factors, whereas general demographics, the IWDs' cognitive capacity, and burden and depression levels of the caregiver were not significant predictors (Hirschman et al.).

Although the research on involvement in medical and long-term-care decision making has identified areas for further inquiry (e.g., who is part of the decision-making team), little work has investigated how involved IWDs are with making decisions about their daily functioning. Decisions about medical treatments are critical to care; however, it is the day-to-day decisions that are omnipresent, and, as argued by Wetle (1991), these daily decisions may contribute more to improved quality of life than larger issues (e.g., medical treatment). For example, Pratt, Jones, Shin, and Walker (1989) found that adult daughters and their chronically ill mothers report that 92% of the time the mother is involved in her own daily care decisions (e.g., what to wear, what to do during the day). In addition, it is suggested that a broader investigation of decision making focus on the decision area of daily care, and such an investigation should include men and those with varying levels of physical and cognitive impairment (Pratt et al.). An IWD's level of decision-making involvement may vary by the level of impairment, the relationship he or she has with the caregiver and family members, or the amount of autonomy and independence that he or she seeks. Therefore, our purpose in this study is twofold: (a) to present a conceptual framework that adapts key components of the stress process to the experience of living with a chronic illness (i.e., dementia), and (b) to understand which constructs within our conceptual framework contribute to the involvement of IWDs in making decisions about daily functioning and care.

Conceptual Model

The Stress Process Model of Chronic Illness

Pearlin and colleagues' operationalization of the Stress Process Model (SPM) is based on the broader stress and coping literature (Lazarus & Folkman, 1984; Pearlin, 1982) and applies key constructs to the stress of caring for a community-dwelling individual with Alzheimer's disease (Pearlin, Mullan, Semple, & Skaff, 1990). Although the original SPM focuses on the stress process of family caregivers, it has been modified and applied to various caregiving situations (Gaugler, Zarit, & Pearlin, 2003; Turner, Pearlin, & Mullan, 1998), and it can serve as a ''heuristic device'' (Pearlin et al., p. 591) for considering similar stress processes and outcomes. The key constructs of the SPM encompass crucial points for understanding the stress process of chronic illness: (a) the unique interaction between individuals with chronic illness and those without the illness (e.g., caregiver, health care professional); (b) the importance of social factors that have an influence on the stress of chronic illness; and (c) the key role that moderators play in either buffering or attenuating the stressful experience of a chronic illness. The Stress Process Model of Chronic Illness (SPMCI) is an adaptation of the original SPM in that the constructs comprising each model component are now specific to the ''care receiver'' and not to the ''caregiver'' (Menne, 2006; also see Figure 1). By offering operationalizations of these key constructs, the SPMCI provides a starting point for exploring the stress process of chronic illness from the point of view of the individual diagnosed and living with the illness, which in this case is dementia.

Operationalization of the SPMCI

Background and Context.—Background and context variables are those sociodemographic characteristics (e.g., age, gender, and education level) of an individual that may contribute either directly or indirectly to the experience of chronic illness, the mediators, or the outcomes. Medical, gerontological, and sociological literatures support the notion that the age, gender, race, or health history of a person with chronic illness will differentially affect his or her illness experience and well-being. For example, research demonstrates that the prevalence of a

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dementia diagnosis increases with age (Skoog, Blennow, & Marcusson, 1996) and that there are differences in stress reactions between men and women (Rieker & Bird, 2000). Research also suggests that African Americans, as compared with Caucasians, are more likely to seek out religion as a way of buffering stressful situations (Siegel & Schrimshaw, 2000). The health history of an individual, such as the total number of health conditions, also contributes directly to the illness-related strains an individual experiences and his or her quality of life (Kahana et al., 2004).

Experience of Chronic Illness.—The experience of living with chronic illness is complex because it simultaneously entails a life event (i.e., the illness) and the ongoing strain of living with the illness; therefore it is necessary to conceptualize collectively the primary stressors (i.e., the illness characteristics) and the secondary strains. In the SPMCI, the experience of living with chronic illness encompasses primary stressors, secondary role strains, and secondary intrapsychic strains. Although these three components of the model are conceptualized together as the experience of chronic illness, in the subsequent analysis each is operationalized and assessed separately (see Figure 1).

Primary Stressors.—Pearlin and colleagues' (1990) articulation of the SPM considers objective and subjective measures of the primary stressor. For an individual with chronic illness, objective measures would include objective diagnosis-related items (e.g., presence of a medical diagnosis). Also measured would be more subjective items related to the individual's impairment levels (e.g., physical, cognitive) as reported by the individual or caregiver.

Secondary Role Strains.—Secondary role strains are those normative roles that may be compromised by the fact that the individual has a chronic illness. Similar to the secondary role strains of caregivers (Pearlin et al., 1990), individual with a chronic illness may experience strains related to the relationship with their caregiver and the relationships with their family.

Secondary Intrapsychic Strains.—Secondary intrapsychic strains are the psychological attributes that may be influenced by the fact that an individual has a chronic illness. An individual's self-esteem, sense of identity, and sense of autonomy are intrapsychic strains that may be altered because an individual has a chronic illness. As we mentioned earlier, the three components of the experience of chronic illness (i.e., primary stressors, secondary role strains, and secondary intrapsychic strains) have an influence on one another. For example, being diagnosed with a disease such as Alzheimer's disease may have an impact on autonomy.

Mediators.—Mediators are often only assessed in terms of how much they attenuate or buffer the relationship between the stressors and the outcomes. The direct effects of mediators on the stressors and the outcomes must also be assessed. An individual's social support and coping techniques (or lack thereof) may change the stress relationship, but it is important to consider how a social support system may directly contribute to enhanced outcomes (e.g., depression). Religiosity is also considered as a mediator because there is evidence that individuals may call upon spiritual resources to aide them through the stressful experience of chronic illness (Daaleman, Cobb, & Frey, 2001).

Outcomes.—As Pearlin (1989) notes, types of outcomes will vary on the basis of the unique orientation of the researchers and the topic they are exploring. In this case, the conceptualization of the SPMCI allows for outcomes related to well-being (e.g., quality of life, decision-making involvement) that may or may not be interrelated. The SPMCI maintains depression and quality of life as outcomes because these constructs capture salient aspects of well-being for individuals with chronic illness. In addition, research suggests that decision-making involvement is related to quality of life (Wetle, 1991). Therefore, the SPMCI posits decision-making involvement as an outcome that is separate from quality of life for the purpose of exploring the unique predictors of decision-making involvement.

Research Questions

This study expands Pearlin and colleagues (1990) SPM to consider the stress process of chronic illness and specifically the chronic illness of dementia. Drawing upon an established SPM provides us with a mechanism to examine specific pathways between stressors and outcomes. In this research we address two primary questions: (a) What are the stressors and strains associated with having cognitive impairment? (b) How are these stressors and strains related to an IWD's decision-making involvement?

Methods

Participants

Data Source.—We drew the data for the present analyses from a larger ongoing study of stress and well-being in families dealing with chronic physical and cognitive health conditions. We collected data from family caregiver (CG)–IWD dyads ($n = 215$), with parallel measures often being used with both members of the dyad.

Sample Eligibility and Acquisition.—We identified potential dyads from client lists of the Family Caregiver Alliance in San Francisco, the Community Services Division of the Benjamin Rose Institute in

Table 1. Measures Available in Testing the Conceptual Model

Variable	Data Source	Coding and Theoretical Range	No. of Scale Items	Alpha
Background and context				
Age	IWD	51–97 years		
Gender	IWD	0 = male; 1 = female		
Race	IWD	0 = Caucasian; 1 = African American		
Education level	IWD	1 = less than HS; 6 = Postgrad. degree		
IWD–CG relationship type	CG	0 = nonspousal; 1 = spousal		
No. of health conditions	CG	0–9 conditions		
Primary stressors				
Diagnosis given by a doctor	CG	0 = no; 1 = yes		
Type of diagnosis	CG	0 = nontechnical diagnosis; 1 = technical diagnosis		
Length of time since diagnosis	CG	0–223 months		
MBPC—Depressive Symptoms	CG	0 = fewer symptoms; 4 = more symptoms	4	.75
MBPC—ADL Problems	CG	0 = fewer problems; 4 = more problems	4	.69
MBPC—Memory Problems	CG	0 = fewer problems; 4 = more problems	5	.80
MMSE	IWD	9 = less cognitive ability; 30 = more cognitive ability		
Secondary strains				
Negative dyadic strain	IWD	0 = less negative strain; 3 = more negative strain	4	.84
Positive dyadic interaction	IWD	0 = less positive strain; 3 = more positive strain	5	.68
Discussed daily care wishes with CG	IWD	1 = have never discussed; 4 = have talked about it a lot		
CG knows daily care wishes	IWD	1 = not at all; 4 = very well		
Involvement with family	IWD	1 = less importance on involvement with family; 3 = more importance on involvement with family	2	.66
Burden to family	IWD	1 = less importance on avoiding being a burden to family; 3 = more importance on avoiding being a burden to family	4	.70
Autonomy–self-identity	IWD	1 = less importance on autonomy or self-identity; 3 = more importance on autonomy or self-identity	4	.71
Outcome				
Decision-Making Involvement Scale	IWD	0 = less involved; 3 = more involved	15	.85

Note: IWD = individual with dementia; CG = caregiver; HS = high school; MBPC = Memory and Behavior Problems Checklist; ADL = activity of daily living; MMSE = Mini-Mental State Examination.

Cleveland, and the University Memory and Aging Center in Cleveland. In order to participate, IWDs must have met the following inclusion criteria at the time of enrollment: be living at home rather than an institutional setting; have a family CG (e.g., spouse or partner, adult child, in-law, grandchild, niece, step-child) who has primary responsibility for providing assistance to the IWD; and have a confirmed diagnosis of or symptoms consistent with a memory-impairing condition (e.g., Alzheimer's disease, vascular dementia, nonspecific or other dementia) or be mildly to moderately cognitively impaired as measured by score on the Mini-Mental State Examination (MMSE).

In order to obtain a diverse sample, we recruited and enrolled IWDs who had not received a confirmed diagnosis. We based this decision on research indicating that minority populations and those with low socioeconomic status have less access to diagnostic procedures (Manton, Patrick, & Johnson, 1987).

Measures

Using the SPMCI as a guide, we chose measures available from the original study (see Table 1). Although the SPMCI posits a mediator relationship between the stressors and strains and the outcome, the available variables did not adequately represent mediators as previously defined. As a result, the subsequent discussion about measures and the secondary analysis plan only focuses on the outcome, background and context, primary stressor, and secondary strain variables. Furthermore, although most of the data are based on self-reports from the IWD, certain items are based on the reports of the CG.

Outcome.—We measured decision-making involvement by using the 15-item Decision-Making Involvement Scale (DMI; Menne, Tucke, Whitlatch, & Feinberg, 2007; Whitlatch, Feinberg, & Tucke,

2005). The DMI was adapted from an inventory originally created to measure choice making among people with developmental disabilities (Conroy & Yuskauskas, 1996). The DMI includes 15 items that assess the extent to which individuals are involved in everyday decision making (e.g., when to get up, what foods to buy). Previous use of the measure with IWDs confirmed that the 15 items comprise one factor and that the internal consistency of the items is high (Cronbach's alpha, $\alpha = 0.85$; Menne et al.).

Background and Context.—Sociodemographic background and context variables are based on either IWD self-reports or reports by the CG. Variables included age, gender, race (0 = Caucasian; 1 = African American), and educational level (1 = less than high school, 2 = some high school, 3 = high school graduate, 4 = some college, 5 = college graduate, and 6 = postgraduate degree). Items based on CG reports include the IWD's health history (number of IWD health conditions) and kin relationship (spouse CG vs nonspouse CG).

Primary Stressors.—The primary stressors are assessed by objective measures related to the individual's diagnosis and cognitive and physical impairments. Diagnosis measures are based on CG reports and include whether the IWD had been diagnosed by a doctor, whether the diagnosis was technical (e.g., Alzheimer's disease, Parkinson's disease) or nontechnical (e.g., nonspecific dementia, no medical diagnosis), and the number of months since diagnosis. The individual's level of cognitive and physical impairment is based on CG responses to the revised Memory and Behavioral Problem Checklist (MBPC). The revised MBPC (Teri et al., 1992) requires CGs to rate the frequency of 26 dementia-related impairments, and 6 functional impairments, as exhibited by the IWD. A previous psychometric analysis on the revised MBPC identified three distinct factors related to memory, depressive behaviors, and activities of daily living (ADLs), with Cronbach's alphas ranging from $\alpha = 0.69$ to $\alpha = 0.80$ (Menne, 2006).

The second measure of level of impairment, the MMSE (Folstein, Folstein, & McHugh, 1975), measures impairment in cognitive ability. The MMSE has a variety of items, and the maximum "high" score of 30 indicates the highest level of cognitive ability. Foreman (1987), as cited by Tombaugh and McIntyre (1992), reported the MMSE to have a Cronbach's alpha reliability score of $\alpha = 0.96$.

Secondary Strain.—Variables operationalized to represent secondary role and intrapsychic strains are based on data collected directly from IWDs. Secondary strains are organized under the rubrics of dyadic strain (representing strain between the IWD and CG), family strain (which represents the strain the IWD feels in regard to his or her family), and intrapsychic strain (representing strain internal to the IWD). Dyadic strain is measured by an adapted version of the Dyadic Relationship Strain scale (Poulshock & Deimling, 1984), which includes two factors: (a) negative dyadic strain (four items; Cronbach's alpha, $\alpha = 0.84$) and (b) positive dyadic interaction (five items; Cronbach's alpha $\alpha = 0.68$; see Menne, 2006). Dyadic strain is also measured by two one-item indicators that assess the IWD's report of the level of communication between CG and IWD: "Have you and your [CG] ever discussed your wishes for daily care?" and "How well do you feel that your [CG] knows your wishes for daily care?"

We used the Values and Preferences Scale (Whitlatch et al., 2005) to query IWDs about the importance of various areas of life, and it provides insight as to what IWDs deem as losses or changes in these areas as related to the dementia diagnosis. A more recent psychometric analysis with IWDs alone (Menne, 2006) identified three factors to the Values and Preferences Scale: autonomy/identity (four items), burden to family (four items), and involvement with family (two items). Thus, these factors represent how much importance an IWD places on autonomy or self-identity, not being a burden to his or her family, and being involved with his or her family. The Cronbach's alphas for these three factors ranged from $\alpha = 0.66$ to $\alpha = 0.71$. Within the SPMCI, the factors of burden to family and involvement with family represent family strain, and autonomy/identity represents intrapsychic strain.

Analysis Plan

To facilitate our understanding of what factors contribute to the involvement of IWDs in making decisions about daily functioning and care, our analysis plan proceeds in two stages. First, we assessed bivariate correlations and interpreted them on the basis of the conservative but traditional two-tailed test of significance. Next, we used hierarchical multiple regression (or blockwise selection; Pedhazur, 1982) to determine the significance of the independent variables in predicting decision-making involvement of IWDs. Hierarchical multiple regression provides a test of statistical significance after the addition of each predetermined block of variables (e.g., background and context, primary stressors), denoting which blocks significantly contribute to the final prediction of the outcome. The increased contribution of each block of variables is represented in the R^2-change value and its related significance.

Results

IWD Descriptive Characteristics

The average age of the IWDs was 76 years, and there was an even number of men and women in the sample (see Table 2). Thirty-one percent of the IWDs

Table 2. Descriptive Statistics (*n* = 215)

	M (SD)
Background and context	
Age	75.89 (9.26)
Gender	0.50 (0.50)
Race	0.31 (0.46)
Education level	3.59 (1.49)
IWD–CG relationship type	0.54 (0.50)
No. of health conditions	2.81 (2.27)
Primary Stressors	
Diagnosis given by a doctor	0.87 (0.33)
Type of diagnosis	0.62 (0.49)
No. of months since diagnosis of memory problems	33.63 (39.93)
MMSE score	21.98 (4.65)
MBPC—Memory Problems	2.49 (1.06)
MBPC—Depressive Symptoms	1.39 (1.00)
MBPC—ADL Problems	1.46 (1.17)
Secondary strains	
Negative dyadic strain	0.89 (0.71)
Positive dyadic interaction	2.11 (0.58)
Discussed daily care wishes with CG	2.30 (1.26)
CG knows daily care wishes	3.56 (0.75)
Involvement with family	2.67 (0.47)
Burden to family	2.70 (0.48)
Autonomy–self-identity	2.57 (0.47)
Outcome	
Decision-Making Involvement Scale	2.30 (0.59)

Note: IWD = individual with dementia; CG = caregiver; MBPC = Memory and Behavior Problems Checklist; ADL = activity of daily living; MMSE = Mini-Mental State Examination.

Table 3. Correlations of Model Variables by Decision-Making Involvement Scale (*n* = 215)

	Decision-Making Involvement Scale
Background and context	
Age	−.16*
Gender	.18**
Race	−.08
Education level	.11
IWD–CG relationship type	−.08
No. of health conditions	.08
Primary Stressors	
Diagnosis given by a doctor	−.14*
Type of diagnosis	−.23**
No. of months since diagnosis of memory problems	−.24**
MMSE score	.26**
MBPC—Memory Problems	−.13
MBPC—Depressive Symptoms	−.16*
MBPC—ADL Problems	−.33**
Secondary Strains	
Negative dyadic strain	−.09
Positive dyadic interaction	.00
Discussed daily care wishes with CG	−.17*
CG knows daily care wishes	.15*
Involvement with family	.21**
Burden to family	.31**
Autonomy–self-identity	.39**

Notes: IWD = individual with dementia; CG = caregiver; MBPC = Memory and Behavior Problems Checklist; ADL = activity of daily living; MMSE = Mini-Mental State Examination.
*Correlation is significant at the *p* = .05 level (two-tailed test).
**Correlation is significant at the *p* = .01 level (two-tailed test).

reported race as African American, and 54% had a spousal CG. On average, IWDs had just fewer than three other health conditions (2.81). The average education level attained in the sample was 3.59, indicating that on average the IWDs had more education than a high school diploma.

Eighty-seven percent of the IWDs had been diagnosed by a doctor prior to their Time 1 interview. Sixty-two percent of the sample had a technical diagnosis (e.g., Alzheimer's disease, Parkinson's disease) and were diagnosed approximately 3 years prior to their interview (x = 33.63 months, SD = 39.93). The average MMSE score was 22 (SD = 4.65; range = 9–30), suggesting a sample that on average had mild cognitive impairment (Tombaugh & McIntyre, 1992). Four IWDs, with MMSE scores greater than 27, did not have a confirmed diagnosis of a memory-impairing condition. We included these IWDs in the analysis because of their self-report (or their CG report) that they had symptoms consistent with a memory-impairing condition.

Bivariate Correlations

Of the background and context variables, only age and gender were significantly correlated with the DMI score (respectively, r = −.16, p < .05; r = .18, p

< .01; see Table 3), suggesting that those who are older and male report less decision-making involvement. The DMI score was significantly correlated with six of the primary stressor variables and with five secondary strain variables. Four of the primary stressor variables were significant at the p < .01 level: type of diagnosis (technical or nontechnical; r = −.23), number of months since diagnosis (r = −.24), MMSE score (r = .26), and MBPC—ADL Problems (r = −.33). These results suggest that those individuals without a technical diagnosis, with fewer months since the diagnosis, and fewer ADL problems (based on CG report) are more involved in decision making. Receiving a diagnosis by a doctor was significantly correlated with the DMI score, suggesting that those who were not diagnosed by a doctor (but still had memory impairment) were more involved in decision making (r = −.14, p < .05). MBPC—Depressive Symptoms (r = −.16, p < .05) was correlated with DMI score, indicating that those with fewer depressive symptoms (based on CG report) are also more involved in decision making. The five secondary strains correlated with the DMI score represented the three types of strains.

Table 4. OLS Regression for a Test of the Model for Predicting Decision-Making Involvement Scale Scores ($n = 215$)

Variable	Model 1			Model 2			Model 3		
	B	β	p	B	β	p	B	β	p
Background and context									
Age	−.02	−.24	.00	−.01	−.17	.01	−.01	−.13	.04
Gender	.22	.19	.02	.21	.18	.02	.20	.17	.01
Race	−.14	−.11	.12	−.13	−.11	.12	−.04	−.03	.64
Education level	.07	.17	.03	.07	.18	.01	.07	.18	.01
IWD–CG relationship type	−.17	−.15	.10	−.27	−.23	.01	−.22	−.18	.02
No. of health conditions	.03	.11	.12	.03	.10	.13	.02	.07	.26
Primary stressors									
Diagnosis given by a doctor				−.13	−.07	.35	−.13	−.07	.31
Type of diagnosis				−.12	−.10	.20	−.10	−.08	.29
No. of months since diagnosis of memory problems				.00	−.13	.03	.00	−.13	.02
MMSE score				.01	.06	.36	.00	.03	.64
MBPC—Memory Problems				.05	.09	.21	.05	.09	.18
MBPC—Depressive Symptoms				−.09	−.15	.02	−.08	−.13	.03
MBPC—ADL Problems				−.16	−.32	.00	−.13	−.27	.00
Secondary strains									
Negative dyadic strain							−.03	−.04	.54
Positive dyadic interaction							.08	.08	.20
Discussed daily care wishes with CG							−.04	−.09	.12
Caregiver knows daily care wishes							.06	.08	.21
Involvement with family							.06	.05	.42
Burden to family							.11	.09	.15
Autonomy–self-identity							.34	.27	.00
Constant	3.16		.00	3.19		.00	1.39		.02
R^2		.12	.00		.31	.00		.42	.00
R^2 change		.12	.00		.19	.00		.12	.00

Note: IWD = individual with dementia; CG = caregiver; MBPC = Memory and Behavior Problems Checklist; ADL = activity of daily living; MMSE = Mini-Mental State Examination.

For dyadic strain, IWDs who had discussed their daily care wishes with their CG tended to report that they were less involved in decision making ($r = −.17, p < .05$). Conversely, IWDs who felt that their CG knew their daily care wishes tended to report being more involved in decision making ($r = .15, p < .05$). The remaining significant correlations indicate that those who place more importance on being involved with family ($r = .21, p < .10$), avoiding being a burden to family ($r = .31, p < .10$), and maintaining autonomy and self-identity ($r = .39, p < .10$) report higher levels of decision-making involvement.

Multiple Regression Predicting the Decision-Making Involvement of IWDs

We used hierarchical multiple regression to determine the significance of the independent variables and SPMCI model components in predicting decision-making involvement of IWDs (see Table 4). The results of the three models predicting DMI score indicate that the R^2 value increases significantly with Steps 1, 2, and 3 ($R^2 = .42, p = .00$). Seven of the variables are significant predictors throughout the analyses: age, gender, education level, number of months since diagnosis, MBPC—Depressive Symptoms (as reported by CG), MBPC—ADL Problems (as reported by CG), and autonomy/self-identity. Type of CG relationship (spousal vs nonspousal), although not a significant predictor when initially added, was significant in Models 2 and 3.

The overall interpretation of Model 3 indicates that eight predictors significantly contribute to the R^2 value of .42 ($p = .00$). This model suggests that IWDs who report more decision-making involvement are younger (β = −.13, $p = .04$), female (β = .17, $p = .01$), have more education (β = .18, $p = .01$), have a nonspousal CG (β = −.18, $p = .02$), have fewer months since their diagnosis (β = −.13, $p = .02$), have fewer depressive symptoms (based on CG report, β = −.13, $p = .03$), exhibit fewer ADL problems (based on CG report, β = −.27, $p = .00$), and place more importance on autonomy/self-identity (β = .27, $p = .00$). Figure 2 shows an overall summary of the significant regression coefficients for the background and context, primary stressor, and secondary strain variables predicting DMI scores.
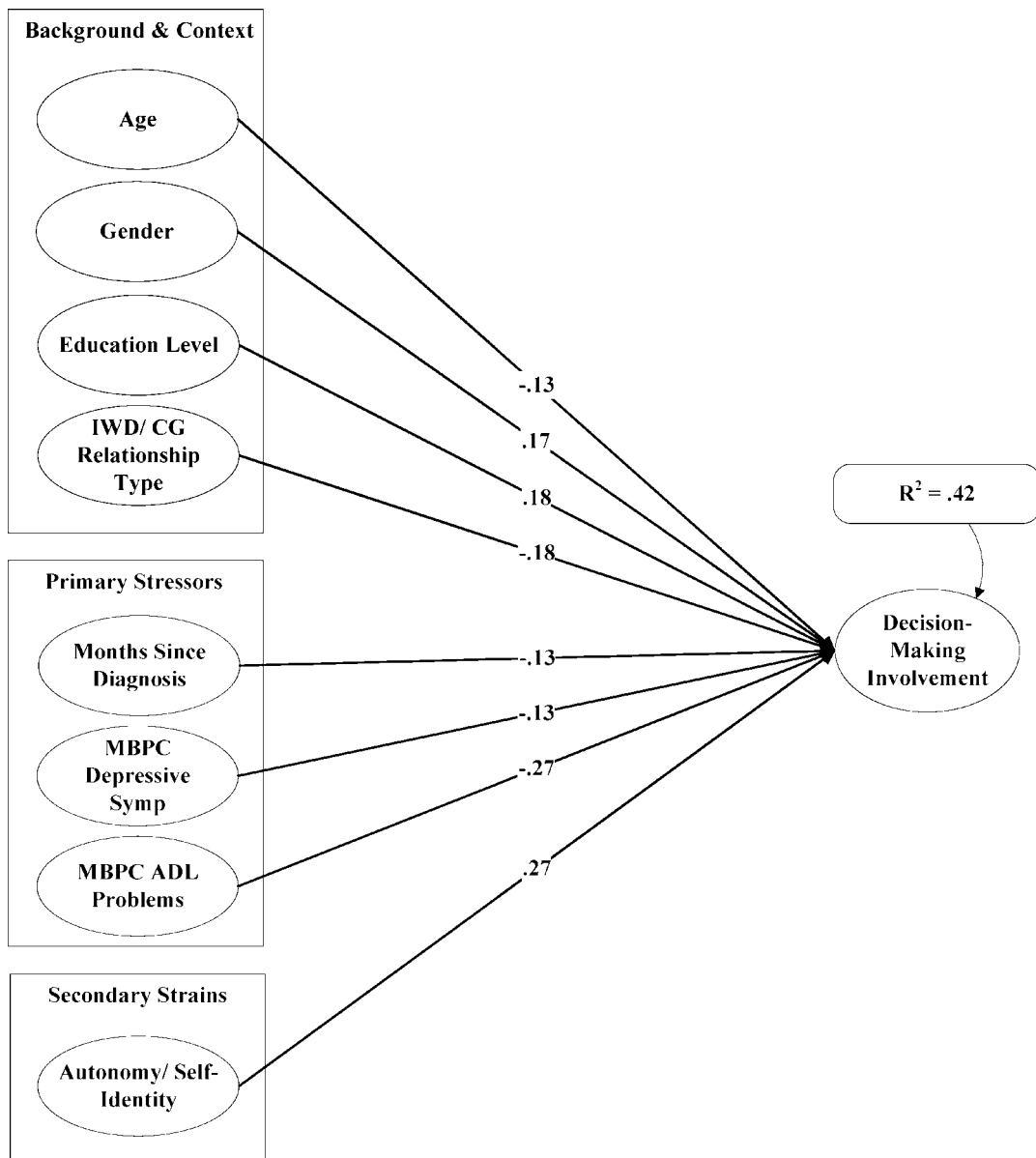
Figure 2. Summary of significant regression coefficients of background and context, primary stressors, and secondary strain variables on the Decision-Making Involvement Scale scores.

Discussion

Results of the present study confirm previous findings (High & Rowles, 1995) that with increased cognitive and physical impairment often comes decreased decision-making involvement. The significant bivariate correlations between decision-making involvement and MMSE scores, number of depressive symptoms, number of ADL problems, and length of time since diagnosis all reinforce the notion that IWDs further along in the illness are less involved in daily care decisions (High & Rowles). The regression results provide additional information about what contributes to the decision-making involvement of IWDs. In the final regression model, education level and CG relationship serve as

significant predictors of decision-making involvement, although neither had a significant bivariate correlation with the outcome. This finding seems to suggest collinearity between the independent variables; however, collinearity diagnostics for the regression analyses indicate that these independent variables were not highly correlated with each other. In the final regression analysis, where all variables were entered simultaneously, a few variables that were significantly correlated with the outcome did not serve as significant predictors (e.g., MMSE score). However, variables such as number of ADL problems and number of depressive symptoms were significantly correlated with and significant predictors of decision-making involvement. These results reinforce the presumption of Pratt and colleagues

(1989) that individuals with higher levels of impairment are less involved in decision making.

Using the SPMCI as a guide, we were able to identify the background characteristics, stressors, and strains related to the decision-making involvement of IWDs. With the addition of each model component (i.e., background and context, primary stressors, and secondary strains), we found significant increases in R^2 values. This suggests the utility of the proposed model components and related variables for understanding IWD decision-making involvement.

Brechling and Schneider (1993) contend that decision-making ability, which is different from decision-making involvement, is contingent upon various factors. In particular, they suggest that the level of the individual's cognitive impairment and the illness stage are components of decision-making ability. Although we could not measure illness stage, the results of the current study indicate that individuals with a more recent diagnosis, who are likely to be less impaired, are more involved in decision-making activities. Early and ongoing decision making by an IWD has the potential to preserve autonomy (Brechling & Schneider) and, in turn, improve the IWD's quality of life (Lawton, 1991; Wetle, 1991).

Interventions that enhance an IWD's involvement in decision making early on in the diagnosis may lead to positive outcomes (e.g., quality of life). Early involvement in decision making has the potential to enhance the IWD's autonomy and provide practitioners and family members with added insight about the identity and preferences of the individual. As Zarit and colleagues state in their work on "memory clubs" for individuals in the early stages of dementia, "the groups empower them [the IWDs] by creating an opportunity to express their needs and participate in planning for their future" (Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004, p. 265). Memory clubs or dyadic interventions, which identify additional mechanisms for enhancing the decision-making involvement of IWDs, may prove effective in improving quality of life (Clare & Cox, 2003; Whitlatch, Judge, Zarit, & Femia, 2006; Zarit et al.).

Although the current study does help us to understand the daily decision-making involvement of IWDs, it is important to note three of its limitations. First, the cross-sectional design of this study limits our ability to make true causal attributions that are premised in the conceptual model. Thus it is not possible to disentangle the causal impact the predictor variables have on the outcome. For example, we cannot definitively posit that level of impairment causes less involvement in decision making. A longitudinal design with multiple waves would allow us to examine how increased impairment is related to decreased decision-making and well-being outcomes (e.g., quality of life). In addition, longitudinal research including cognitively impaired and cognitively intact older adults is needed to determine the causal impact of physical impairment and cognitive impairment on the decision-making involvement of older adults.

Second, because this research involved a secondary analysis, there are inherent weaknesses. To begin, the variables available for analysis did not always ideally match the constructs proposed in the SPMCI. For example, because of limited measures it was not possible for us to test the mediation effect of social support or religiosity on the relationship between the stressors or strains and decision-making involvement. In addition, IWDs were not queried about their level of awareness about their diagnosis. It is speculated that the awareness level of the IWD plays a crucial role in decision-making involvement (Hirschman et al., 2005).

Unlike previous studies (Hirschman et al., 2005; Karlawish et al., 2002), this analysis only considers decisions about daily functioning, not decisions about long-term-care needs. By focusing on decisions about daily functioning, we are more likely to understand the autonomy and identity of the individual because the individual's preferences and desires are shared in a more holistic manner (Wetle, 1991). Examining decisions of daily functioning allows for a more complete picture and understanding of the individual.

Further research warrants consideration of whether decision-making involvement is truly a precursor to or rather a component of well-being. Bamford and Bruce (2000) have proposed that an individual's sense of autonomy is one element of his or her quality of life. This may suggest that, on one hand, autonomy and decision-making involvement contribute to an IWD's quality of life. On the other hand, the interrelationships among autonomy, decision-making involvement, and well-being do not preclude autonomy and decision-making involvement as antecedents to IWD well-being. First, continued involvement in making decisions such as "what to eat at meals" or "what to do in your spare time" offers the IWD an opportunity to maintain his or her autonomy (Menne et al., 2002). Second, involvement in decision making and maintenance of autonomy may contribute to less depression and enhanced well-being even as impairments worsen for the IWD. Regardless of whether decision-making involvement is a precursor to or a component of well-being, our results indicate that decision-making involvement plays a significant role in the lives of IWDs. Health care practitioners, case managers, home care aides, and family members can reinforce the individual's autonomy by keeping him or her involved in decision making, which may also help to enhance the quality of life and well-being of the individual (Gentile, 1991).

References

Albert, S. M., Jacobs, D. M., Sano, M., Marder, K., Bell, K., Devanand, D., et al. (2001). Longitudinal study of quality of life in people with advanced Alzheimer's disease. *American Journal of Geriatric Psychiatry, 9*, 160–168.

Alzheimer's Association. (2005, May 15). Fact sheet: Alzheimer's disease

statistics. Retrieved on February 7, 2006, from http://www.alz.org/Resources/FactSheets/FSAlzheimerStats.pdf

Alzheimer's Disease International. (2006). Common questions: How many people have dementia? Retrieved on February 7, 2006, from http://www.alz.co.uk/alzheimers/faq.html

Bamford, C., & Bruce, E. (2000). Defining the outcomes of community care: The perspectives of older people with dementia and their carers. *Ageing and Society, 20,* 543–570.

Brechling, B. G., & Schneider, C. A. (1993). Preserving autonomy in early stage dementia. *Journal of Gerontological Social Work, 20*(1/2), 17–33.

Clare, L., & Cox, S. (2003). Improving service approaches and outcomes for people with complex needs through consultation and involvement. *Disability & Society, 18,* 935–953.

Conroy, J. W., & Yuskauskas, A. (1996). *Independent evaluation of the Monadnock Self-Determination Project.* Ardmore, PA: The Center for Outcomes Analysis.

Daaleman, T. P., Cobb, A. K., & Frey, B. B. (2001). Spirituality and well-being: An exploratory study of the patient perspective. *Social Science & Medicine, 53,* 1503–1511.

Davis, R. (1989). *My journey into Alzheimer's disease.* Wheaton, IL: Tyndale House.

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12,* 189–198.

Foreman, M. D. (1987). Reliability and validity of mental status questionnaires in elderly hospitalized patients. *Nursing Research, 36,* 216–220.

Gaugler, J. E., Zarit, S. H., & Pearlin, L. I. (2003). Family involvement following institutionalization: Modeling nursing home visits over time. *International Journal of Aging and Human Development, 57,* 91–117.

Gentile, K. M. (1991). A review of the literature on interventions and quality of life in the frail elderly. In J. E. Birren, J. E. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly* (pp. 74–88). San Diego, CA: Academic Press.

High, D. M., & Rowles, G. D. (1995). Nursing home residents, families, and decision making: Toward an understanding of progressive surrogacy. *Journal of Aging Studies, 9,* 101–117.

Hirschman, K. B., Joyce, C. M., James, B. D., Xie, S. X., & Karlawish, J. H. T. (2005). Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *The Gerontologist, 45,* 381–388.

Kahana, E., King, C., Kahana, B., Menne, H., Webster, N., Dan, A., et al. (2004). Successful aging in the face of chronic disease. In M. L. Wykle, P. J. Whitehouse, and D. L. Morris (Eds.), *Successful aging through the lifespan: Intergenerational issues in health* (pp. 101–126). New York: Springer.

Karlawish, J. H. T., Casarett, D. J., & James, B. D. (2002). Alzheimer's disease patients' and caregivers' capacity, competency and reasons to enroll in an early phase Alzheimer's disease clinical trial. *Journal of the American Geriatrics Society, 50,* 2019–2024.

Kerner, D. N., Patterson, T. L., Grant, I., & Kaplan, R. M. (1998). Validity of the Quality of Well-Being scale for patients with Alzheimer's disease. *Journal of Aging and Health, 10,* 44–61.

Lawton, M. P. (1991) A multidimensional view of quality of life. In J. E. Birren, J. E. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly* (pp. 3–27). San Diego, CA: Academic Press.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York: Springer.

Manton, K. G., Patrick, C. H., & Johnson, K. W. (1987). Health differentials between blacks and whites: Recent trends in mortality and morbidity. *The Millbank Quarterly, 65*(Supp. 1), 129–199.

McGowin, D. F. (1993). *Living in the labyrinth: A personal journey through the maze of Alzheimer's.* New York: Delacorte Press.

Menne, H. L. (2006). *A stress process model of chronic illness: Understanding the well-being and decision-making involvement of*

individuals with dementia. Unpublished doctoral dissertation, Case Western Reserve University, Cleveland, Ohio.

Menne, H. L., Kinney, J. M., & Morhardt, D. J. (2002). "Trying to continue to do as much as they can do": Theoretical insights regarding continuity and meaning making in the face of dementia. *Dementia: The International Journal of Social Research and Practice, 1,* 367–382.

Menne, H. L., Tucke, S. S., Whitlatch, C. J., & Feinberg, L. F. (2007). *Decision-making involvement scale for individuals with dementia and family caregivers.* Manuscript submitted for publication.

Pearlin, L. I. (1982). The social context of stress. In L. Goldberger & S. Breznitz (Eds.), *Handbook of stress* (pp. 367–379). New York: Free Press.

Pearlin, L. I. (1989). The sociological study of stress. *Journal of Health and Social Behavior, 30,* 241–256.

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30,* 583–594.

Pedhazur, E. J. (1982). *Multiple regression in behavioral research: Explanation and prediction* (2nd ed.). New York: CBS College.

Poulshock, S. W., & Deimling, G. T. (1984). Families caring for elders in residence: Issues in the measurement of burden. *Gerontology, 39,* 230–239.

Pratt, C. C., Jones, L. L., Shin, H. Y., & Walker, A. J. (1989). Autonomy and decision making between single older women and their caregiving daughters. *The Gerontologist, 29,* 792–797.

Rieker, P. P., & Bird, C. E. (2000). Sociological explanations of gender differences in mental and physical health. In C. E. Bird, P. Conrad, & A. M. Fremont (Eds.), *Handbook of medical sociology* (pp. 98–113). Upper Saddle River, NJ: Prentice-Hall.

Sabat, S. R., & Collins, M. (1999). Intact social, cognitive ability, and selfhood: A case study of Alzheimer's disease. *American Journal of Alzheimer's Disease, 14,* 11–19.

Siegel, K., & Schrimshaw, E. W. (2000). Perceiving benefits in adversity: Stress-related growth in women living with HIV/AIDS. *Social Science & Medicine, 51,* 1543–1554.

Skoog, I., Blennow, K., & Marcusson, J. (1996). Dementia. In J. E. Birren (Ed.), *Encyclopedia of gerontology* (Vol. 1, pp. 383–403). San Diego, CA: Academic Press.

Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S., & Vitaliano, P. (1992). Assessment of behavioral problems in dementia: The revised Memory and Behavior Problems Checklist. *Psychology and Aging, 7,* 622–631.

Tombaugh, T. N., & McIntyre, N. J. (1992). The Mini-Mental State Examination: A comprehensive review. *Journal of the American Geriatrics Society, 40,* 922–935.

Turner, H. A., Pearlin, L. I., & Mullan, J. T. (1998). Sources and determinants of social support for caregivers of persons with AIDS. *Journal of Health and Social Behavior, 39,* 137–151.

Wetle, T. (1991). Resident decision making and quality of life in the frail elderly. In J. E. Birren, J. E. Lubben, J. C. Rowe, & D. E. Deutchman (Eds.), *The concept and measurement of quality of life in the frail elderly* (pp. 279–296). San Diego, CA: Academic Press.

Whitlatch, C. J., Feinberg, L. F., & Tucke, S. S. (2005). Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. *The Gerontologist, 45,* 370–380.

Whitlatch, C. J., Judge, K., Zarit, S. H., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. *The Gerontologist, 46,* 688–694.

Zarit, S. H., Femia, E. F., Watson, J., Rice-Oeschger, L., & Kakos, B. (2004). Memory club: A group intervention for people with early-stage dementia and their care partners. *The Gerontologist, 44,* 262–269.