

Research Article

Involvement of Hospitalized Persons With Dementia in Everyday Decisions: A Dyadic Study

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Abstract

Background and Objectives: To examine the involvement of persons with dementia (PWDs) in everyday decision making from the perspectives of hospitalized PWDs and their family caregivers, and to identify determinants thereof.

Research Design and Methods: Using multilevel modeling, we examined cross-sectional data collected prospectively from 42 family care dyads regarding the care values of the PWD.

Results: Both members of the dyad rated the PWD, on average, as being “somewhat involved”. There was a significant amount of variability around the average perceptions of PWD involvement in decision making for both PWDs ($\chi^2 = 351.02$, $p < .001$) and family caregivers ($\chi^2 = 327.01$, $p < .001$). Both PWDs and family caregivers were significantly more likely to perceive greater PWD involvement in decision making when the family caregiver reported the PWD as valuing autonomy. Additionally, PWDs were significantly more likely to report greater involvement when they had greater cognitive function. Finally, family caregivers perceived significantly greater involvement of the patient in decision making when they reported less strain in the relationship. Together, autonomy, relationship strain, cognitive function, and care-related strain accounted for 38% and 46% of the variability in PWDs’ and family caregivers’ perceptions, respectively, of the PWD’s decision-making involvement.

Discussion and Implications: Although research indicates that decision-making abilities decline with advancing dementia, these results imply that working with families to support PWDs in their value of autonomy and mitigate strain in the dyad’s relationship may help prolong PWDs’ decision-making involvement.

Keywords: Interpersonal context, Informal caregiving, Multilevel modeling, Patient autonomy

Involving older adult patients in decisions about their health and future care is becoming standard practice, particularly through the promotion of models of shared decision making (Elwyn et al., 2012) and a sustained focus on improving advance care planning and end-of-life decision making (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Drought & Koenig, 2002; Schmid, Allen, Haley, & Decoster, 2010). The continued involvement of a person with dementia (PWD) in decision making and care planning, though

not standard practice, is an important goal for both the PWD and the family caregiver (Fetherstonhaugh, Tarzia, & Nay, 2013; Samsi & Manthorpe, 2013). Although researchers have often examined the involvement of PWDs in medical and treatment decisions (Hirschman, Xie, Feudtner, & Karlawish, 2004; Horton-Deutsch, Twigg, & Evans, 2007; Karel, Gurrera, Hicken, & Moye, 2010; Karlawish, Casarett, Propert, James, & Clark, 2002), it is the involvement in “everyday” decisions about daily care, activities,

and functioning that is often most important to PWDs (Feinberg & Whitlatch, 2002; Menne & Whitlatch, 2007; Murphy & Oliver, 2013; Samsi & Manthorpe, 2013). Involvement in these everyday decisions give PWDs a sense of purpose and help them to avoid feeling marginalized (Fetherstonhaugh et al., 2013). There is also evidence that there are fewer depressive symptoms in the family caregiver and better quality of life in both PWD and family caregiver when the PWD is more involved in everyday decision making (Menne, Judge, & Whitlatch, 2009; Menne, Tucke, Whitlatch, & Feinberg, 2008; Samsi & Manthorpe, 2013).

The substantial challenges of involving PWDs in decision making within the acute care setting have recently been highlighted (Greener et al., 2012; Nilsson, Rasmussen, & Edvardsson, 2013). Compared to other older adults, PWDs experience 3 times as many hospitalizations (Thies & Bleiler, 2013). Readmission and mortality rates in hospitals are also higher among PWDs than other older adults (Callahan et al., 2012). Some PWDs have described the experience of a hospitalization as stressful and threatening (Edvardsson & Nordvall, 2008), and the loss of independence in completing activities of daily living is common for PWDs during a hospitalization. For family caregivers, the hospitalization of a relative with dementia has been associated with high levels of burden and depressive symptoms (Epstein-Lubow et al., 2012; Shankar, Hirschman, Hanlon, & Naylor, 2014). The adverse effects of hospitalizations on PWDs and their family caregivers likely create substantial challenges to decision making among PWD-family caregiver dyads. It is critical to understand decision making in this context due to the unique time pressures of hospital discharge planning, and the opportunity to include both members of the dyad. Discharge planning begins at admission for hospitalized patients, and decisions about everyday aspects of the PWD's life (e.g., choosing who to help with care or where to live) are an inevitable part of the discharge plan. Yet, there are no known studies that have examined the involvement of hospitalized PWDs in everyday decisions from either the PWD's or the family caregiver's point of view.

Dementia is a shared context for the PWD-family caregiver dyad. A dyadic perspective (PWD and family caregiver as a unit) is important to the understanding of decision making about everyday aspects of life with dementia, particularly since the lives of this type of care dyad are so intertwined (Samsi & Manthorpe, 2013). Whereas the family caregiver's perspective has historically been used in research to represent the PWD (Cotrell & Schulz, 1993), the PWD's perspective is important to include because involvement of PWDs in decision making is important to the family caregiver and it is also associated with better quality of life for the dyad (Menne et al., 2008, 2009; Samsi & Manthorpe, 2013). Furthermore, including the PWD's perspective is important to maintaining personhood (Bartlett & O'Connor, 2007; Woods, 2001), and it is

warranted given the evidence supporting the reliability of PWDs' self-report. For example, PWDs have consistently and reliably reported on their own quality of life (Logsdon, Gibbons, McCurry, & Teri, 2002), well-being (Mak, 2011), pain (Fisher et al., 2002), depressive symptoms (Parmelee, Lawton, & Katz, 1989), and care values and preferences (Whitlatch et al., 2005), even with a moderate amount of cognitive impairment. At the same time, impairments to executive function and insight, which are common in dementia, affect PWDs' abilities to make decisions independently (Kensinger, 2009; Orfei et al., 2010; Sorensen, Mak, & Pinquart, 2011), and as a result, family caregivers' are often required to make the crucial link between what a PWD values and the particular decisions at hand (Gillick, 2013). Thus, when considered together as a dyad, the two perspectives allow for an examination of decision making that reflects the joint involvement of PWD and family caregiver, which is often necessary and optimal in the context of dementia.

Conceptual Framework

In order to represent both dyad members' perspectives conceptually, the framework for this study was derived from the Stress Process Model (SPM) for family caregivers of PWDs (Pearlin, Mullan, Semple, & Skaff, 1990), as well as subsequent versions that have been operationalized for individuals with chronic illness (Menne & Whitlatch, 2007), and more recently, for persons with dementia (Judge, Menne, & Whitlatch, 2010). The three iterations share in common a model encompassing primary stressors and secondary strains that are influential upon one another and together on an outcome of wellbeing such as quality of life or depression (Pearlin et al., 1990), or decision-making involvement of PWDs (Menne & Whitlatch, 2007). The three main components that influence such outcomes are: (a) primary stressors related to dementia/dementia caregiving, both objective (e.g., pathologies of the disease) and subjective (e.g., overload of care tasks or psychological distress of living with dementia), (b) secondary role strains (i.e., strains that occur as a result of adapting to life with dementia), and (c) secondary intrapsychic strains, described by Pearlin and colleagues (1990) as strains on "dimensions of self-concept" (e.g., self-esteem).

In the conceptualization of stressors and strains for this study we drew upon the three versions of the SPM (Judge et al., 2010; Menne & Whitlatch, 2007; Pearlin et al., 1990) and integrated them with the resulting literature to maintain a dyadic perspective of the illness experience. Thus, we operationalized the primary objective stressor related to the dementia illness experience as cognitive function (Judge et al., 2010; Pearlin et al., 1990), the primary subjective stressor as care-related strain (Menne et al., 2009; Pearlin et al., 1990), the secondary role strain as dyadic relationship strain (Judge et al., 2010; Menne & Whitlatch, 2007; Sebern & Whitlatch, 2007), and the secondary intrapsychic strain as

the importance of autonomy to the PWD (Menne et al., 2009; Menne & Whitlatch, 2007). Other studies outside the SPM literature have also shown that cognitive impairment and care-related strain are significantly associated with the family caregiver's perception of the PWD's decision-making involvement (Hirschman et al., 2004; Karlawish et al., 2002). Few studies, however, have examined the PWD's involvement in everyday decision-making from both perspectives (Adler, 2010; Boyle, 2013; Menne & Whitlatch, 2007; Samsi & Manthorpe, 2013) and no prior studies have focused on decision-making of the dyad during hospitalization—an event that often calls into question aspects of the PWD's independence (e.g., activities of daily living) and the dyad's life at home (e.g., the care arrangement).

The purpose of this study was to examine the involvement of PWDs in everyday types of decisions according to the perspectives of hospitalized patients with dementia and their family caregivers, and to identify factors associated with the dyad's perception of greater involvement of PWDs in decision making.

Design and Methods

Participants for this study were recruited from three adult inpatient acute care units in a university hospital in the Pacific Northwest. Approval was obtained from the Institutional Review Board for this study. Patients were admitted to hospital units where recruitment took place for a wide range of medical and surgical diagnoses (e.g., pneumonia, cardiac dysrhythmias, and hip fracture). A convenience sample of 42 dyads was enrolled that met the following eligibility criteria.

Inclusion Criteria

PWDs were eligible if they were aged 65 or older, admitted to an acute care unit (with any diagnosis), had symptoms consistent with mild to moderate dementia, and self-reported a probable or current diagnosis of an irreversible progressive dementia: Alzheimer's disease, vascular dementia, Lewy body dementia, or frontotemporal dementia. Family caregivers were eligible if they were aged 21 or older, nominated by the PWD as the primary family caregiver (primary family caregiver was defined as the family member who is most involved in care at home). To be eligible, PWDs had to score at least 13 on the Mini-Mental State Examination (MMSE), which corresponds to reliable, consistent reporting in previous studies using this criterion (Feinberg & Whitlatch, 2001; Logsdon, Gibbons, McCurry, & Teri, 2002; Parmelee, Lawton, & Katz, 1989; Whitlatch, Feinberg, & Tucke, 2005).

Exclusion Criteria

Dyads were ineligible if either the PWD or family caregiver was unable to speak English, or if the PWD had unresolved delirium or altered level of consciousness, which was

assessed by the direct care registered nurse (RN) prior to screening for interest.

After the investigator screened patient records for potentially eligible participants (confirming dementia diagnosis through chart review), the PWD's direct care RN screened patients and family caregivers for interest in the study. The researcher met with each member of the dyad to confirm interest, assess eligibility, and obtain informed consent. Individual members of each dyad completed one private interview in-person within the acute care unit, typically within 2–3 days following admission. Participants were provided with written cards to aid memory about response scales and answered verbal questions from the researcher. Responses were recorded by the researcher on a laptop using RedCap, an electronic data capture and storage system.

Measures

Outcomes

Decision-making involvement of the PWD was measured in PWDs and family caregivers using equivalent versions of the Decision-Making Involvement Scale developed specifically for the dementia care dyad (Menne et al., 2008). The measure consists of 15 items, scored on a 4-point scale from 0 (not involved at all), to 3 (very involved). Each member of the dyad responded with their perception of how involved the PWD is in everyday types of decisions (e.g., where to live, when to get medical care, what to eat at meals). The reliability in this study was excellent (PWD $\alpha = .89$; family caregiver $\alpha = .87$). Further details of the process for scoring of the measure is described under "parallel scales" in the Analytic Approach section.

Independent Variables

Cognitive status was screened and measured in PWDs with the MMSE (Folstein, Folstein, & McHugh, 1975). The MMSE is designed for clinician assessment of 11 cognitive domains spanning aspects of orientation, working memory, language, delayed recall, attention, and comprehension. The scale range is 0–30, with higher scores indicating higher cognitive function. It is used widely in research and has good reliability (test–retest $r = .89$) and validity (predictive and concurrent validity) among PWDs (Fillenbaum, Heyman, Wilkinson, & Haynes, 1987; Mitchell, 2009; Tombaugh & McIntyre, 1992).

Care-related strain was measured in family caregivers using the Role Overload scale (Pearlin et al., 1990), which assesses the extent to which caregiver's time and energy are exhausted by the demands of caring for the person with dementia. Caregivers responded to 3 items regarding how worn-out and overloaded their care role makes them feel using a Likert-type scale from 1 (not at all) to 4 (very much). The items were summed for a scale range of 3–12. Higher scores indicate high levels of care-related strain. The reliability in this sample was adequate ($\alpha = .75$).

Relationship strain was measured in family caregivers using the 5-item Dyadic Strain subscale of the Dyadic

Relationship Scale (Sebern & Whitlatch, 2007). Each item is a statement of a potential source of strain in the relationship, for which family caregivers rated their level of agreement from 1 (strongly disagree) to 4 (strongly agree). An example item is: "Because of helping my family member, I feel angry toward her/him." Items were averaged for a scale range of 1–4, with higher scores indicating more perceived relationship strain. The reliability in this sample was good ($\alpha = .85$).

The PWD's value of autonomy was measured in family caregivers using the autonomy subscale of the Care Values scale, which was developed specifically for caregiving dyads in which the care recipient is a person with cognitive impairment (Whitlatch, Piiparinen, & Feinberg, 2009). The autonomy subscale has 7 items that describe care values around autonomy (e.g., do things for him/herself). The items were rated according to the importance of each value to the PWD on a 3-point scale. The total score was averaged for a scale range of 1–3, with higher scores indicating that the family caregiver perceived the PWD to place more importance on their autonomy. The reliability in this sample was adequate ($\alpha = .79$).

Analytic Approach

Descriptive statistics and Pearson's correlations between study variables were conducted using the software program Stata, version 14 (Statacorp, 2015). Analysis of the dyadic data was conducted using multilevel modeling and the software program HLM, version 7 (Raudenbush, Bryk, & Congdon, 2011). The multivariate outcomes model (separate PWD/family caregiver outcomes) can be achieved using multilevel modeling while still estimating and controlling for the degree of shared variance in the dyad. In this study, level 1 data included PWDs and family caregivers, which were nested within the level 2 PWD-family caregiver dyad (the unit of analysis). HLM uses full information maximum likelihood (FIML) to estimate parameter values, given all existing data. In this study there were less than 1% missing data on the outcome variable for PWDs and less than 6% missing data on the outcome variable for family caregivers. The level 1 (unconditional) model estimated the average values and the variability around the averages for both the PWD's and family caregiver's perceptions of the PWD's decision-making involvement. Predictors were introduced in level 2 to explain the variability around the average.

Level 1 Model

Within-dyad variation was modeled at level 1, where the outcome is the sum of the true score and measurement error using the following formula, originally described by Barnett, Marshall, Raudenbush & Brennan (1993), and more recently adapted by other dyadic researchers (Lyons & Sayer, 2005; Pruchno, Wilson-Genderson, & Cartwright, 2009). In the equation,

$$\text{Decision}_{ij} = \beta_{1j}(\text{PWD}_{ij}) + \beta_{2j}(\text{CG}_{ij}) + r_{ij}$$

Decision_{ij} represents the outcome parallel score *i* in dyad *j*. PWD is an indicator variable taking on a value of 1 if the response was obtained from the PWD, or taking on a value of 0 if the response was obtained from the family caregiver. Similarly, CG is an indicator variable taking on a value of 1 if the response was obtained from the family caregiver, or taking on a value of 0 if the response was obtained from the PWD. The latent true scores of perceptions of the PWD's decision-making involvement for PWDs and family caregivers are represented by β_{1j} and β_{2j} , respectively. The within-dyad residuals, r_{ij} , are estimated separately for PWD and family caregiver. Thus, PWDs' average perceptions of their own decision-making involvement (Decision) is the sum of their latent true score (β_{1j}) plus measurement error (r_{ij}); or, family caregivers' average perceptions of PWDs' decision making involvement (Decision) is the sum of their latent true score (β_{2j}) plus measurement error (r_{ij}).

Parallel Scales

In order to provide adequate information to estimate measurement error variances for both PWD and the family caregiver, parallel scales were created for both members of the care dyad. These procedures (Barnett, Marshall, Raudenbush, & Brennan, 1993; Sayer & Klute, 2005) entailed matching items from the decision-making involvement measure into pairs based upon the closeness of their standard deviations to create 7 pairs with one item from each pair randomly assigned to one of two scales. This process resulted in two parallel scales with equal variance and reliability for each member of the dyad (a total of four scores for each dyad). Although the parallel scales method is not always possible when there are too few items on the measure, or when variances of parallel scales are too dissimilar, we were confident that our use of parallel scales was appropriate given that these conditions were satisfied in our study. Finally, the level 1 model also produces a tau correlation, capturing the correlation between PWDs' and family caregivers' scores of the PWD's decision-making involvement.

Level 2 Model

Between-dyad variation was modeled at level 2. In the equations,

$$\beta_{1j} = \gamma_{10} + \gamma_{11}\text{MMSE}_j + \gamma_{12}\text{STRAIN}_j + \gamma_{13}\text{RELAT}_j + \gamma_{14}\text{AUTON}_j + u_{1j}$$

$$\beta_{2j} = \gamma_{20} + \gamma_{21}\text{MMSE}_j + \gamma_{22}\text{STRAIN}_j + \gamma_{23}\text{RELAT}_j + \gamma_{24}\text{AUTON}_j + u_{2j}$$

the parameters for latent true scores of PWDs (β_{1j}) and family caregivers (β_{2j}) became the outcome variables. Based upon the SPM and supporting literature from studies previously conducted in the community setting, independent variables (MMSE = the PWD's cognitive function; STRAIN = care-related strain, RELAT = relationship strain; and AUTON = the PWD's value of autonomy) were included in level 2 conditional models. The proportion of

variability explained by these independent variables was calculated for each of the outcome variables (the PWD's and family caregiver's perceptions of the PWD's decision-making involvement) as follows: $(\tau_{00} [\text{Level 1 unconditional model}] - \tau_{00} [\text{Level 2 conditional model}]) / \tau_{00}$ (Level 1 unconditional model), where τ_{00} represents the variance component (either PWD or caregiver).

Results

Patients with dementia were mean age 80 ± 8 years, predominantly non-Hispanic white ethnicity/race (95%), had an average MMSE score of 21 ± 4 , and a slight majority (55%) were male. The most common dementia diagnosis among patients was Alzheimer's disease (40%), followed by vascular dementia (29%), mixed or unknown dementia type (24%), fronto-temporal dementia (5%), and Lewy body dementia (2%). Family caregivers were age 61 ± 13 years, predominantly non-Hispanic white ethnicity/race (93%), mostly female (75%), and were either adult children (70%) or spouses (30%) of patients. See Table 1 for additional demographic and descriptive data. Bivariate correlations (Table 2) between study variables and other potentially influential variables were also examined in order to better understand the sample characteristics and directions for future research. Although there were no statistically significant correlations in this small sample, the PWD's perception of greater involvement in decision making was negatively correlated with greater years spent caregiving ($r = -.19, p = .234$), and positively correlated with the PWD's years of education ($r = .217, p = .185$) and female gender ($r = .252, p = .107$). The family caregiver's perception of greater involvement of the PWD in decision making was negatively correlated with being in a non-spousal relationship ($r = -.181, p = .263$).

Multilevel Modeling Results

At level 1 (see Model 1, Table 3), average ratings of the PWD's decision-making involvement were $\beta_{1j} = 2.11 \pm 0.10, p < .001$ and $\beta_{2j} = 2.09 \pm 0.10, p < .001$ for PWDs and family caregivers, respectively, indicating that, on average, both members of the dyad perceived the PWD as being "somewhat" involved in everyday decisions. The tau correlation between PWD and family caregiver ratings of the PWD's decision-making involvement was high at .76. There was a significant amount of variability around the average perceptions of PWD involvement in decision-making from the perspective of both PWDs ($\chi^2 = 351.02, p < .001$) and family caregivers ($\chi^2 = 327.01, p < .001$).

Based on level 2 results (Model 2, Table 3), both PWDs and family caregivers were significantly more likely to perceive greater PWD involvement in decision making when the family caregiver reported the PWD as valuing autonomy (see Table 3). PWDs were significantly more likely to report greater involvement when they had better cognitive function. Family caregivers were significantly more likely

Table 1. Sample Demographics ($N = 42$ Dyads) and Measure Descriptives

	PWD	CG
	Mean (SD) or %	Mean (SD) or %
Age in years	79.81 (7.76)	61 (12.95)
Female	45.24%	75%
Education (> high school diploma)	69%	84.60%
Race/Ethnicity		
White (Non-Hispanic)	95.24%	92.50%
Black/African American	2.38%	2.50%
Native American/Pacific Islander	0%	0%
Asian	2.38%	5%
Hispanic/Latino	2.38%	2.50%
Marital status (married/partnered)	40.00%	62.50%
Relationship to patient		
Wife	—	22.50%
Husband	—	7.50%
Adult daughter	—	50.00%
Adult son	—	17.50%
Daughter-in-law	—	2.50%
Dementia type		
Alzheimer's disease	40.48%	—
Vascular	28.57%	—
Fronto-temporal	4.76%	—
Lewy bodies	2.38%	—
Other (Mixed or Unknown)	23.81%	—
Cognitive function (MMSE, range 12–27)	20.55 (3.86)	—
Care-related strain (Role overload, scale 3–12)	—	7.9 (2.62)
Relationship strain (scale 1–4)	—	2.02 (.72)
PWD's value of autonomy (scale 1–3)	—	2.19 (.50)

Note: CG = family caregiver; PWD = person with dementia; MMSE = Mini-mental state examination; SD = standard deviation. Ages 90 years or older were all recorded as 90+ to protect identity.

to report greater PWD involvement when they perceived less strain in their relationship with the PWD. Together, autonomy, relationship strain, cognitive function, and care-related strain accounted for 38% and 46% of the variability in PWDs' and family caregivers' perceptions, respectively, of the PWD's decision-making involvement. According to Cohen's F^2 , the effect sizes corresponding to the proportion of variance explained by Level 2 results were $f^2 = .61$ for the PWDs' model and $f^2 = .85$ for the family caregivers' model.

Discussion

The current study was a dyadic examination of the decision-making involvement of PWDs in everyday types of decisions, and it is one of the first such studies known to include hospitalized PWDs and their family caregivers. There are several important findings. First, PWDs and family caregivers shared similar average ratings of the PWD as being "somewhat" involved in decision making, which is

Table 2. Pearson’s Correlations Between Study Variables and Other Potentially Influential Variables

1. PWD DMI scale	1	2	3	4	5	6	7	8	9	10
2. Spouse/Non-spouse	0.001	—								
3. FM years caregiving	-0.193	0.125	—							
4. PWD age in years	-0.103	-0.326*	-0.14	—						
5. PWD female gender	0.252	-0.298	-0.159	0.329*	—					
6. PWD years education	0.217	0.108	0.216	-0.212	-0.530***	—				
7. Cognitive impairment	0.411**	0.025	-0.108	-0.223	0.383*	-0.183	—			
8. FM role overload	-0.093	0.046	0.252	-0.092	-0.101	-0.012	0.108	—		
9. FM relationship strain	-0.242	0.146	-0.056	-0.148	-0.138	-0.146	-0.084	0.199	—	
10. PWD’s autonomy	0.323*	-0.173	-0.312*	-0.057	0.017	0.098	0.095	-0.036	0.039	—
11. Family DMI scale	0.674***	-0.181	-0.005	-0.065	0.145	0.124	0.236	0.122	-0.17	0.558***

Note: DMI Scale = decision-making involvement scale [Menne et al., 2008](#); FM = family member; PWD = person with dementia.
p* < .05; *p* < .01; ****p* < .001.

Table 3. Multilevel Results Predicting Perceptions of the PWD’s Decision-Making Involvement (*N* = 42 dyads)

	Model 1			Model 2		
	β	<i>SE</i>	<i>t</i>	β	<i>SE</i>	<i>t</i>
Fixed effects (robust <i>SE</i>)						
PWD intercept	2.11	.10	21.10***	2.09	.08	24.83***
Cognitive impairment				0.07	.03	2.87**
Care-related strain				-0.02	.03	-0.69
Perception of PWD’s autonomy				0.43	.15	2.85**
Perception of relationship strain				-0.20	.11	-1.84
Family member intercept	2.09	.10	21.20***	2.09	.08	26.47***
Cognitive impairment				0.02	.02	1.14
Care-related strain				0.05	.03	1.58
Perception of PWD’s autonomy				0.74	.16	4.75***
Perception of relationship strain				-0.21	.09	-2.17*
Random effects						
	Variance component		χ^2	Variance component		χ^2
Patient	0.37		351.02***	0.23		217.38***
Family member	0.35		327.01***	0.19		191.26***

Note: PWD = person with dementia; *SE* = standard error. Note that cognitive impairment was measured from the PWD’s self-report, whereas care-related strain, perceptions of the PWD’s autonomy, and perceptions of relationship strain were measured from family caregiver’s reports only.
p* < .05; *p* < .01; ****p* < .001.

comparable to studies of dyads in the community setting ([Menne & Whitlatch, 2007](#)). Second, there was significant variability around the average perceptions for both PWDs and family caregivers, confirming that the use of a method such as MLM is necessary in order to further examine this variability and providing evidence that there is heterogeneity across dyads. Third, several determinants chosen according to the SPM were identified as being significantly associated with the variability in perceptions of the hospitalized PWD’s decision-making involvement. This finding indicates that dyads’ appraisals of the PWD’s involvement in decision-making may be affected by the stress process. Finally, determinants differed across PWD/family caregiver models, reinforcing the need for a dyadic examination of decision making within the care dyad with dementia.

The family caregiver’s perception of the PWD’s value of autonomy was a significant determinant of both PWD

and family caregiver ratings of the PWD’s decision-making involvement. According to the SPM, the diminishing value of autonomy in the PWD can place an intrapsychic strain on perceptions of the PWD’s involvement in making decisions, potentially lowering both PWD and family caregiver ratings ([Menne & Whitlatch, 2007](#)). As other researchers have pointed out, preserving autonomy in PWDs and supporting their involvement in decision-making are related goals ([Fetherstonhaugh et al., 2013](#); [Menne et al., 2008](#); [Samsi & Manthorpe, 2013](#)). However, in this study we included the family caregiver’s perception of how important autonomy is to the PWD, the difference being that we measured the value of autonomy rather than a perception of how much independence remains in the PWD. This difference is critical since dementia continually threatens autonomy, but may not diminish how important autonomy is to a PWD. Recent perspectives on achieving person-centered care

underscore the importance of moving away from how to compensate for what PWDs cannot do, and instead focus on how to promote the PWD's contributions and identity (Vernooij-Dassen & Moniz-Cook, 2016). Working with family caregivers to show that they understand and support PWDs in their value of autonomy may be an important protective factor helping to prolong PWDs' decision-making involvement.

Family caregivers in this study perceived greater involvement of the PWD in decision making when they rated strain in their relationship with the PWD as being lower. This finding is similar to another study using the SPM as a framework, where relationship strain is considered a secondary role strain that is influential on the perceptions of the PWD's decision-making involvement (Menne & Whitlatch, 2007). It is likely that family caregivers are in a better position to support PWDs' decision-making involvement when they enjoy less strain in the relationship. Since this is cross-sectional data, it is also possible that when PWDs are more involved in decision making, the family caregiver perceives the dyad's relationship as less strained. Future longitudinal work is needed to untangle these associations.

We found support in this study for the conceptualization of cognitive impairment as a primary stressor on PWDs' perceptions of their decision-making involvement, as described previously in the SPM literature (Judge et al., 2010; Pearlin et al., 1990). Previous studies conducted in the community setting have also demonstrated that PWDs' perceptions of their decision-making involvement were higher when the PWD had greater cognitive function (Karlawish et al., 2002; Menne et al., 2008). A recent literature review of dementia decision making found that across six studies, the severity of cognitive impairment was strongly correlated, and even predictive of, lower levels of the PWD's decision-making involvement (Miller, Whitlatch, & Lyons, 2016). However, in this study family caregivers did not associate the PWD's decision-making involvement with cognitive ability, indicating that cognitive impairment may not be as influential on family caregivers' perceptions as it is on PWDs' perceptions when other influential stressors and strains (i.e., relationship strain) are included in the analyses. The PWDs included in this study had mild to moderate dementia, with an average MMSE score of 21 ± 4 . Whereas PWDs' cognitive function may weigh on their own perceptions of their decision-making involvement from early in the disease process, family caregivers' perceptions may not be significantly affected by cognitive function until the extent of impairment is greater and more observable (e.g., moderate to severe dementia).

This study was limited in its generalizability by small sample size and lack of diversity. Sample size dictated that few independent variables be entered into models, which constrained the study in several ways. Firstly, potentially confounding variables such as education level (Hirschman et al., 2005; Menne & Whitlatch, 2007), age (Hirschman

et al., 2004; Menne et al., 2008), gender (Menne & Whitlatch, 2007), and kinship type (Hirschman et al., 2005) were not included due to sample size, which was constrained by the number of dyads per parameter estimated (in this case 4 determinants for 42 dyads). Secondly, the small sample in this study limited the selection of independent variables to only one variable representing each type of stressor or strain from the SPM, and to only one dyad member's perception representing each variable. This latter limitation constrained the ability to simultaneously examine actor and partner effects on the outcome of decision-making involvement of PWDs. In order to fully explore the influence that dyad members' thoughts and perceptions have on one another in this area, future research is needed with larger samples and reports from both members of the care dyad on potential determinants of decision-making involvement of PWDs.

Yet, there were notable strengths to the study, including the novel inpatient hospital setting, dyadic measures and data collection, and an analytic approach (i.e., MLM) appropriate for dyadic data. By including the perspective of both members of the dyad at the outcome-level, we highlighted the complexities of decision making for dyads with dementia, which clearly extend beyond the question of whether or not a PWD is involved in the process. Other researchers have emphasized the importance of including the PWD and family caregiver together as a dyad in discharge planning during a hospitalization (Bloomer, Digby, Tan, Crawford, & Williams, 2016). This study adds to the literature by providing evidence of extensive variability in PWD involvement in decision making in the acute care setting, and by suggesting that there are differential determinants of perceptions of PWD involvement (e.g., cognitive impairment, relationship strain) depending on whose perspective of decision making is solicited (i.e., PWD's or family caregiver's). Future studies should thus continue to include both PWD and family caregiver perspectives while working toward addressing the modifiable aspects of decision-making involvement of PWDs.

The inpatient hospital setting is one place in which many decisions about post-hospital care and everyday living are made, and where most PWDs will find themselves at some point during the dementia trajectory. Although hospital discharge planning in the context of dementia is complex—and our measure of decision making involvement was not specific to all the decisions that go into the discharge plan—this study has implications for using a hospitalization as an opportunity to bring together patients with dementia and their family members to make decisions as a dyad. A hospitalization may also be an important time to focus on assisting dyads in planning together for everyday care at home while there are multiple resources, specialists, and other providers on hand. The results from this study suggest that, in order to appreciate the challenges of including the PWD in decision making, the nurse or clinician may need to first

assess the extent of cognitive impairment in PWDs and the amount of strain in the dyad's relationship, since both of these factors have the potential to diminish the dyad's perceptions of the PWD's decision-making involvement. Relationship strain is a modifiable factor, capturing the salient interpersonal context of the dyad. Providing family caregivers with resources to address strain in the dyad's relationship could lead to improvements in the PWD's involvement in decision-making. Finally, assessing family caregivers' perceptions of the importance of autonomy to the PWD, and encouraging their support of it, may help sustain the PWD's involvement in decision-making despite the challenges of doing so in an acute care environment. Ultimately, this study provides evidence that the family caregiver's perception of the PWD's values is a significant aspect of including the PWD in the types of decisions that make up the discharge plan. Thus, the family caregiver could be the PWD's most crucial advocate for remaining involved in decision-making and optimizing care planning for the dyad with dementia in the acute care setting.

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