

Understanding Discrepancy in Perceptions of Values: Individuals With Mild to Moderate Dementia and Their Family Caregivers

Allison M. Reamy, MS,^{1,*} Kyungmin Kim, MA,¹ Steven H. Zarit, PhD,¹ and Carol J. Whitlatch, PhD²

¹Department of Human Development and Family Studies, Pennsylvania State University, University Park.
²Benjamin Rose Institute on Aging, Cleveland, Ohio.

*Address correspondence to Allison M. Reamy, MS, Department of Human Development and Family Studies, Pennsylvania State University, University Park, PA 16802. E-mail: amr383@psu.edu

Received August 25, 2010; Accepted January 26, 2011
Decision Editor: William J. McAuley, PhD

Purpose of the Study: We explore discrepancies in perceptions of values and care preferences between individuals with dementia (IWDs) and their family caregivers. **Design and Methods:** We interviewed 266 dyads consisting of an individual with mild to moderate dementia and his or her family caregiver to determine IWDs' beliefs for 5 values related to care (autonomy, burden, control, family, and safety). We used multilevel modeling to investigate if there are dyadic level discrepancies in beliefs and what factors are associated with such discrepancies. **Results:** Caregivers consistently underestimated the IWD's values for all five values. Discrepancies were associated primarily with caregivers' beliefs about the IWD's involvement in decision making. Race was also associated with the discrepancies for control and safety, whereas cognitive functioning of the IWD was associated with the discrepancy for burden. **Implications:** Many caregivers do not have an accurate depiction of the IWD's values, yet, caregivers will become the surrogate decision makers for IWDs as dementia progresses. These findings indicate the need for assessments of values and preferences in care and to develop programs that assess values, consider the caregiver's beliefs about care, and improve communication within the dyad in the early stages of dementia.

Key Words: Caregiving, Decision making, Care preferences

Research on family caregiving has generally focused on understanding caregiver burden and stress (i.e., Crespo, López, & Zarit, 2005). Fewer studies, however, have examined the perspectives of the caregiver and the care receiver as a unit (Lyons, Zarit, Sayer, & Whitlatch, 2002; Martire et al., 2008; Meyler, Stimpson, & Peek, 2007; Zweibel & Lydens, 1990) and focus instead on either the older person or the caregiver as independent entities (Schreiner, Morimoto, Arai, & Zarit, 2006; Zarit, Femia, Kim, & Whitlatch, 2010). Yet, understanding the dyadic perspective in caregiving is fundamental. Dyadic coping theory, a variant of systems theory, posits that dyads have a mutual and interdependent response to shared stressors such that they negotiate emotions elicited from shared experiences and participate in joint problem solving (Berg & Upchurch, 2007; Bodenmann, 1995). Each person's actions affect and are affected by the other individual. Ledermann and colleagues (2010) discuss four forms of dyadic coping: supportive (one helps the other), delegated (one takes responsibility to reduce partner's stress), negative (hostile, ambivalent, or superficial coping), and

joint (equal participation). These forms become particularly relevant when considering situations where caregivers must become substitute decision makers for their care receivers. As individuals with dementia (IWDs) gradually lose cognitive and functional ability, their caregivers predictably slide into a role of progressive surrogacy, making more decisions of greater significance on behalf of the IWD (Elliott, Gessert, & Peden-McAlpine, 2009). As this happens, there is likely to be a shift to more negative or delegated coping strategies, whereby the decisions may reflect the caregiver's perspectives and lose the dyadic focus.

From an ethical standpoint, it is essential to include IWDs in their own care decision making, to the extent possible, in order to support their autonomy and act in their best interests as they decline (Zarit & Braungart, 2007). Perspectives drawn from theories of person-centered care (Downs, Small, & Froggatt, 2006; Kitwood, 1997) and narrative ethics (e.g., Baldwin, 2005; Elliott et al., 2009) posit that the person's story should be the central source of meaning in care. IWDs' views, however, are generally not taken into consideration, even when dementia is still mild (Menne & Whitlatch, 2007). This lack of involvement may lead to increased dependence and depression (Zarit & Braungart, 2007). Caregivers, in turn, may not know the IWDs' preferences for important care issues and may be reluctant to make decisions (i.e., use respite care) that the IWD might actually support. Thus, for ethical and pragmatic reasons, there is a need to improve dyadic communication and consider IWDs' perspectives when making care decisions.

Although dementia poses a major challenge to autonomy, growing evidence indicates that individuals with mild to moderate dementia can consistently and accurately report on their own preferences and values in care (i.e., psychosocial preferences in long-term care decision making such as self-identity, relationships, or health; Clark, Tucke, & Whitlatch, 2008; Feinberg & Whitlatch, 2001; Karel, Moye, Bank, & Azar, 2007; Whitlatch, Feinberg, & Tucke, 2005a, 2005b; Whitlatch, Piiparinen, & Feinberg, 2009). These findings support the need to understand self-reported values of IWDs to inform care decision making. As suggested by dyadic coping theory, the IWD's preferences need to be placed in the context of the caregiving dyad, where caregivers can draw upon this understanding to facilitate more effective coping and planning for care, especially when the IWD's own decision making ability becomes impaired.

Although evidence supports the reliability of IWDs' reports of values and preferences and theory validates the inclusion of such values in care decisions, less is known about whether family caregivers understand these values. Literature addressing the use of advance directives suggests that surrogate decision makers identify patient preferences correctly less often than would be predicted by chance alone (Fagerlin, Ditto, Hawkins, Schnieder, & Smucker, 2002). Studies looking at more general values report that discrepancies between care receivers' values and caregivers' understanding of values are common for both individuals with (Whitlatch et al., 2009) and without dementia (Carpenter, Lee, Ruckdeschel, van Haitsma, & Feldman, 2006; McCullough, Wilson, Teasdale, Kolpakchi, & Skelly, 1993). Whitlatch and colleagues (2009) found that caregivers underestimated the importance of many values for IWDs, whereas Carpenter et al. reported that child caregivers underestimate their parents' desire for enrichment and personal growth while overestimating their desire for self-dominion, diversionary activities, and enlisting others in care. Although describing such discrepancies, prior research has not explored possible factors associated with these discrepancies for IWDs. Dyadic coping theory would predict that discrepancies could be related to factors that affect a shared vision of the challenges posed by dementia care (Berg & Upchurch, 2007). These factors could be demographic (e.g., race, education), relational (e.g., type of relationship of the caregiver to the IWD—spouse or child, dyadic strain), and/or individual characteristics (e.g., caregivers' beliefs or IWD's cognitive ability). Investigation of factors associated with incongruence in values could better inform our understanding of dyadic decision making in care and how to intervene socially and medically to improve communication for an IWD.

The aim of this study is to determine if there are discrepancies between IWDs and caregivers in perceptions of the IWD's care values and to understand what factors are associated with such discrepancies. Consistent with previous findings, we hypothesize that there will be a discrepancy in report between IWDs and caregivers on IWD's values. We believe that IWDs can report in a reliable way on their beliefs, even though experiencing some cognitive impairment. In contrast, the task for caregivers of reporting on the IWD's values involves balancing their own needs and the

concerns of their relative. Thus, caregivers' views and beliefs about care may enter into their reports. Therefore, second, we hypothesize that given caregiver stress related to making decisions in care for an IWD, caregiver beliefs about care will be significantly associated with this discrepancy.

Methods

Participants

The sample consisted of 266 caregiving dyads of an individual with mild to moderate dementia (IWD) and his or her family caregiver. The sample combined participants from three complimentary studies that investigated dyadic relations between caregivers and IWDs. Participants were recruited from research and direct service organizations in the San Francisco Bay area and Cleveland, Ohio. To be eligible, caregivers had to be the primary family caregiver of the IWD, and the IWD had to be living at home, and either have a confirmed diagnosis of dementia from a physician or have symptoms of progressive memory problems. Respondents typically had scores between 13 and 27 on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). Inclusion, however, was not based solely on MMSE scores and took into account other indicators of functioning and education. Some individuals with high MMSE scores (27 or more; $n = 44$) were included because they had a confirmed diagnosis of dementia. Conversely, some individuals with low MMSE scores (below 13; $n = 4$) were included. These individuals had low levels of formal education, their overall functioning was more typical of mild to moderate dementia, and they could complete the research interview. For more information about recruitment, see Whitlatch and colleagues (2009).

Caregivers were predominantly women (77.1%, $n = 205$), ranging from 29 to more than 90 years of age ($M = 64.94$ years, $SD = 13.78$; at the request of the institutional review board ages above 90 were recoded to 90, to minimize the possibility of identifying any individual based on age). Caregivers were primarily spouses (54.5%, $n = 145$) or children (36.5%, $n = 97$) of the IWD. One third of the caregiver sample ($n = 88$) was African American. About half of the IWDs were women (51.5%, $n = 137$) and 31.1% ($n = 82$) were African American. IWDs ranged between 39 and more than 90 years of age ($M = 76.34$ years, $SD = 9.24$; see Table 1)

Table 1. Characteristics of Caregivers and IWDs

	<i>M</i>	<i>SD</i>	Range
Caregiver's			
Age	64.94	13.78	29–90+
Education	4.21	1.21	1–6
Income	5.14	2.10	1–8
Female (<i>yes = 1</i>)	0.77	0.42	0–1
African American (<i>yes = 1</i>)	0.33	0.47	0–1
Spouse (<i>yes = 1</i>)	0.55	0.50	0–1
Child (<i>yes = 1</i>)	0.36	0.48	0–1
Employed (<i>yes = 1</i>)	0.40	0.49	0–1
Coresidence (<i>yes = 1</i>)	0.63	0.48	0–1
Best interests	2.81	0.20	2–3
Decision involvement of IWD	2.20	0.92	0.06–4
Dyadic strain	1.45	0.39	0–2.45
IWD's			
Age	76.20	9.01	39–90+
Female (<i>yes = 1</i>)	0.52	0.50	0–1
African American (<i>yes = 1</i>)	0.31	0.46	0–1
MMSE score	22.24	4.52	9–30
Dyadic strain	1.57	0.44	0–3

Notes: Dyad $N = 266$. IWD = individual with dementia; MMSE = Mini-Mental State Examination.

Procedure

Each member of the dyad was interviewed separately in his or her own home. Visual aids for response choices were used for both IWDs and caregivers to minimize burden on memory. Although the content of the interviews differed slightly across the three merged samples, complete data were available on values and preferences of the IWD in care (from both the caregiver's and the IWD's points of view) and for the other measures used in these analyses.

Measures

Demographics.—Sociodemographic characteristics were obtained for each individual, including age, gender, race, highest level of education, employment status, coresidence, and annual income (an 8-point scale ranging from 1 being *less than \$8,000* to 8 being *\$60,000 or more*). Race was coded 1 for African American and 0 for others. Education ranged from 1 (*less than high school*) to 6 (*postgraduate degree*). As the sample mean for IWDs' level of education was significantly lower than caregivers' education, $t(247) = 7.05$, $p < .001$, only caregiver education was used in our analyses to account for higher levels of education within dyads. Kin relationship between IWD and caregiver was categorized into three groups: child,

Table 2. Value Scales Items and Cronbach Alphas

	Items (“The importance . . .”)	α for caregiver report	α for IWD report
Autonomy	To come and go as one pleases To organize one’s own daily routines To spend one’s money the way he/she wants	.76	.69
Burden	To avoid being a physical burden on one’s family To avoid being an emotional burden on one’s family To avoid being a financial burden on one’s family For the caregiver not to put life on hold for the IWD	.81	.74
Control	To avoid family conflict To choose a specific individual to help To exclude a specific individual from helping To have money to leave for one’s family	.53	.59
Family	To have something to do To be with family or friends To be a part of family celebrations	.60	.61
Safety	To be safe from crime To feel safe in one’s own home To be in touch with someone in an emergency	.79	.70

Notes: Dyad N = 214–266. IWD = individual with dementia.

spouse, or other. Gender, age, employment status, and coresidence were excluded from analyses as they were all highly confounded with kin relationship (e.g., almost all male caregivers were spouses). Income was excluded due to nonrandom missing data.

Dependent Measures.—The Values and Preferences Scale (Whitlatch et al., 2005b) consists of 37 items that assess the IWD’s values and preferences in care. In line with dyadic perspectives, both caregivers and IWDs rated the importance of IWD’s values and preferences in care. Items were rated on a 3-point scale ranging from 1 (*not at all important*) to 3 (*very important*). An exploratory factor analysis was performed to determine naturally occurring scales. In accordance with a person-centered perspective, we used the IWD’s reports in this analysis. Thirteen items were dropped because they had little variance (i.e., over 80% of respondents endorsed one answer choice) or had factor loadings <.40. The analysis yielded seven factors: *autonomy*, *burden*, *control*, *continuity*, *family*, *safety*, and *quality of care*. Comparable scales were then constructed with caregiver reports, and the internal reliabilities were examined using Cronbach’s alpha. The scales for *continuity* and *quality of care* had alphas that were too low to be considered reliable (.44 and .46 for caregiver and IWD report, respectively, on continuity and .24 and .46 for quality of care) and were dropped from analyses. The remaining factors had marginal to adequate alphas (between .59 and .74 for the IWD reports and .53 and .81 for the caregiver reports). Reliabilities were fairly consistent across scales for IWDs and caregivers.

Next, we performed a group equivalence test in LISREL to determine if the factor structure was similar for caregivers. Model fit statistics were used to compare two models: Model 1 in which factor loadings were freely estimated for both groups and Model 2 where the factor loadings were fixed commonly between groups. Although change in the chi-square was significant between Model 1 and Model 2 ($\Delta\chi^2 = 48.221$ [$\Delta df = 13$], $p < .001$), tests of practical fit indicate that the difference between the fit of the two models was trivial (change in root-mean-square error of approximation [RMSEA] = 0.000, change in comparative fit index [CFI] = 0.001). These results suggest that the model for caregivers was equivalent to that for IWDs (a table illustrating the model fit is available upon request). Table 2 shows the items for each scale and alphas. Table 3 presents means and differences in scores for caregivers and IWDs.

Independent Measures.—Drawing on dyadic coping theory (e.g., Berg & Upchurch, 2007), independent measures included factors that could affect perspectives within a caregiving relationship. In addition to demographic characteristics,

Table 3. Caregivers’ and IWDs’ Report of Care Values of the IWD, M (SD)

	Caregiver	IWD	t
Autonomy	7.07 (1.89)	7.54 (1.62)	3.66***
Burden	10.04 (2.32)	10.87 (1.88)	4.89***
Control	9.19 (1.98)	9.51 (2.08)	1.92†
Family	10.15 (1.75)	10.51 (1.58)	2.82**
Safety	7.85 (1.66)	8.39 (1.16)	5.39***

Notes: Dyad N = 214–266; paired sample t test. IWD = individual with dementia.

† $p < .10$; ** $p < .01$; *** $p < .001$.

the measures included are described below (see Table 1 for means and range of scores).

IWD's Cognitive Functioning.—To assess global cognitive functioning, IWDs completed the MMSE (Folstein et al., 1975). The mean score in this sample was 22.24 ($SD = 4.52$; $\alpha = .78$).

Caregiver's Beliefs About Care.—Best Interests. Seven items developed by Whitlatch and Feinberg (2003) measured the importance for the caregiver to consider the IWD's best interests in care. Responses were coded on a scale of 1 (*not at all important*) to 3 (*very important*). A mean item response was computed ($\alpha = .57$). Higher scores indicated greater importance for considering the IWD's best interests in care decisions.

Decision-Making Involvement of the IWD. Caregivers and IWDs completed a 15-item scale that assessed how involved the IWD is in decision making around daily activities; however, only the caregiver report was used in the primary analyses (Menne, Tucke, Whitlatch, & Feinberg, 2008; Menne & Whitlatch, 2007). Examples of items included decisions about visiting with friends, when to go to bed, and what to do in his/her spare time. Responses were coded on a 5-point scale: 0 (*not involved at all*) to 4 (*very involved*). Mean item scores were calculated ($\alpha = .93$). Higher scores indicate greater perceived involvement of the IWD in making decisions.

Dyadic Strain.—Caregivers and IWDs responded to questions regarding their current relationship on the 11-item Dyadic Relationship Scale (Bass, Tausig, & Noelker, 1989; Sebern & Whitlatch, 2007). One item was judged inappropriate for IWDs (“I felt that s/he made requests over and above what s/he needed”) and was omitted from their interview. Items were scored 0 (*strongly disagree*) to 3 (*strongly agree*). Scores were reversed for the positive items. A mean item score was calculated with higher scores indicating greater perceived strain ($\alpha = .69$ for caregivers and $\alpha = .65$ for IWDs).

Data Analysis

To analyze the data at the level of the dyad, we used multilevel modeling (SAS PROC MIXED; Littell, Milliken, Stroup, & Wolfinger, 1996),

which accounts for the interdependence of individuals within each dyad. This technique allows for prediction at both the level of the outcome and the level and direction of differences in reports of the outcome within pairs (Maguire, 1999). In the multilevel model, individual observations of caregivers and IWDs were nested within the dyad (the unit of analysis) and analyzed at two levels. At Level 1, observations from each dyad member were fit to a regression line on an indicator variable (caregiver or IWD). This regression model was summarized by two parameters: an intercept, representing the mean level of importance of the value reported for each matched pair, and a slope, which captures the discrepancy in level of importance of the value between the dyad members. We modeled the individual value score (Y_{ij}) for i th member in the j th dyad as

$$Y_{ij} = \beta_{0j} + \beta_{1j}(\text{Relation}_{ij}) + e_{ij},$$

which is a function of an intercept (β_{0j} , the mean score across dyads), a slope (β_{1j} , the degree of discrepancy between the dyad members), and individual-level errors of prediction (e_{ij} ; The indicator variable, “Relation” was coded -0.5 for caregiver and 0.5 for IWD. Therefore, a negative coefficient for discrepancy indicates that caregivers reported higher levels of importance on the specific value than IWDs; a positive coefficient for discrepancy indicates that IWDs reported higher levels of importance of the value than caregivers.). We used an unstructured covariance matrix to specify the random effects. At Level 1, if the dyadic discrepancy (slope) and mean (intercept) have significant variance components (random effects), it is appropriate to proceed with a Level 2 model in which other variables can be included to explain the variation in these parameters (Bryk & Raudenbush, 1992).

To address Hypothesis 1, which states there will be a discrepancy in report between caregivers and IWDs on IWD's values, we tested if the slope in the Level 1 models was significant. To address Hypothesis 2, that caregiver beliefs will be significantly associated with this discrepancy at the level of the dyad, we included two groups of factors at Level 2: caregiver characteristics (spouse/child, race, education, best interests, decision-making involvement of the IWD, and dyadic strain) and IWD characteristics (MMSE and dyadic strain). In order to interpret the factors associated with the discrepancy, both the intercept (mean score of dyadic

Table 4. Baseline Model: Dyadic Means and Discrepancies of Caregiver's and IWD's Reports on Care Values

Parameter	Autonomy		Burden		Control		Family		Safety	
	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>
Fixed effects										
Intercept (mean)	7.32***	0.09	10.47***	0.10	9.34***	0.09	10.33***	0.08	8.12***	0.07
Slope (discrepancy) ^a	0.47***	0.13	0.84***	0.17	0.34*	0.17	0.36**	0.13	0.55***	0.10
Random effects										
Variance (mean)	1.63***	0.17	2.16***	0.22	1.89***	0.20	1.36***	0.15	0.83***	0.12
Variance (discrepancy)	2.91***	0.38	5.98***	0.67	5.72***	0.64	2.78***	0.37	0.38*	0.23
Covariance (mean and discrepancy)	-0.46*	0.18	-0.93***	0.28	0.19	0.25	-0.27	0.17	-0.72***	0.13
-2 log likelihood	2,059.9		2,251.4		2,230.2		2,012.6		1,790.8	

Notes: Dyad *N* = 214–266. Observations *N* = 523–526. IWD = individual with dementia.

^aNegative discrepancy scores indicate that the caregiver is reporting more importance than the IWD is reporting; positive discrepancy scores indicate that the IWD is reporting more importance than the caregiver is reporting.

†*p* < .10; **p* < .05; ***p* < .01; ****p* < .001.

reports) and the slope (discrepancy between dyadic reports) were outcome variables modeled at Level 2,

$$\beta_{0j} = \gamma_{00} + \gamma_{01j}W_{qj} + U_{0j},$$

$$\beta_{1j} = \gamma_{10} + \gamma_{11j}W_{qj} + U_{1j},$$

where W_{qj} are characteristics used as predictors of the effect of β_{pj} , and γ_{pqj} is the corresponding coefficient representing the direction and strength of association between characteristic W_{qj} and β_{pj} . The error term (U_{pj}) contains the effect of unmeasured characteristics that do not vary across dyad members.

Results

The first hypothesis predicted a discrepancy in report between caregivers and IWDs on IWDs' values. Level 1 of the multilevel models indicates that all five discrepancy coefficients were significant and positive (see Table 4). IWDs reported a higher level of importance for all five values than the caregivers. The Level 1 models also showed that there were significant random effects (variability between dyads) in both level and slope across all five values.

To test the second hypothesis that caregiver beliefs are significantly associated with the discrepancy in caregiver and IWD report, we entered possible factors that could be associated with discrepancies at Level 2 of the multilevel model (see Table 5). The caregiver's report of how involved the IWD is in decision making about his/her daily care was significantly associated with the

discrepancy scores for all five values. As shown in Figure 1, when caregivers report their relative is more involved in decision making, then caregivers are more likely to give a higher importance to that specified value than IWDs. Conversely, when caregivers believe that the IWD has less involvement in care decision making, then they report less importance for values than IWDs. Inclusion of the IWD's self-report of decision-making involvement in the model did not alter these findings and was not significantly related to discrepancies in values.

Among the other variables tested, only cognitive impairment and race were significantly associated with discrepancies in value reports. Cognitive impairment is significantly associated with the discrepancy in report of burden, such that, when IWDs score higher on the MMSE (i.e., higher cognitive ability), they are more likely to report higher scores for value of burden (avoiding being a burden) than caregivers. For the values of control and safety, African American caregivers are more likely to report higher scores than the IWDs. Neither caregivers' ratings of the importance of taking the IWD's best interests into account nor dyadic strain was associated with discrepancies. As a follow-up analysis, we tested for an interaction of race and MMSE. The interaction term was significant only for discrepancies in autonomy. For dyads with a non-African American caregiver, IWDs with higher MMSE scores were less likely to place importance on the value of autonomy as compared with their caregivers, whereas there is no significant association for dyads with an African American caregiver.

Table 5. Factors Associated With Caregiver–IWD Discrepancies in Reporting IWDs’ Values and Preferences in Care

	Autonomy		Burden		Control		Family		Safety	
	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>
Intercept (mean)	7.39***	0.35	10.75***	0.41	9.09***	0.38	10.12***	0.34	8.31***	0.32
Slope (discrepancy) ^a	1.07*	0.52	0.97	0.77	0.61	0.72	1.10†	0.57	1.27**	0.45
Predictors of mean										
Caregiver’s characteristics										
Spouse	-0.26	0.36	-0.50	0.42	0.24	0.39	0.23	0.35	-0.49	0.33
Child	-0.00	0.35	0.04	0.41	0.14	0.38	0.36	0.34	-0.40	0.32
Race	-0.09	0.22	-0.46†	0.26	-0.41†	0.24	-0.49*	0.21	0.30	0.20
Education	-0.04	0.08	0.05	0.10	0.01	0.09	0.02	0.08	-0.04	0.07
Best interests	0.81†	0.44	0.28	0.53	0.82*	0.49	0.67	0.43	0.70†	0.40
Decision involvement of IWD	0.78***	0.13	0.57**	0.15	0.47**	0.14	0.32*	0.13	0.26*	0.12
Dyadic strain	0.29	0.24	-0.30	0.29	-0.08	0.27	-0.35	0.24	-0.31	0.22
Race × MMSE	0.07	0.05	—	—	—	—	—	—	—	—
IWD’s characteristics										
MMSE	0.03	0.02	0.04*	0.03	0.01	0.02	-0.01	0.02	-0.03	0.02
Dyadic strain	-0.10	0.21	0.17	0.25	0.35	0.23	0.04	0.21	0.24	0.19
Predictors of discrepancy										
Caregiver’s characteristics										
Spouse	-0.35	0.54	0.19	0.79	0.40	0.63	-0.70	0.29	-0.59	0.46
Child	-0.29	0.52	-0.45	0.77	0.11	0.62	-0.97	0.57	0.19	0.45
Race	-0.52	0.33	0.06	0.48	-1.07*	0.40	0.16	0.36	-0.67*	0.28
Education	-0.01	0.12	-0.12	0.18	-0.04	0.15	-0.06	0.13	-0.07	0.11
Best interests	-0.59	0.66	-1.51	0.99	-1.78†	0.86	-0.96	0.73	-0.76	0.57
Decision involvement of IWD	-1.16***	0.20	-0.73**	0.28	-0.64*	0.23	-0.62**	0.22	-0.56***	0.17
Dyadic strain	-0.22	0.36	0.10	0.53	0.59	0.46	0.10	0.40	0.01	0.28
Race × MMSE	0.20**	0.07	—	—	—	—	—	—	—	—
IWD’s characteristics										
MMSE	-0.06†	0.03	0.12**	0.05	0.07	0.04	-0.01	0.04	0.05†	0.03
Dyadic strain	0.12	0.31	0.19	0.47	0.17	0.44	-0.06	0.35	0.49†	0.28
Random effects										
Variance (mean)	1.23***	0.16	1.85***	0.23	1.58***	0.20	1.20***	0.16	0.96***	0.14
Variance (discrepancy)	2.21***	0.37	6.18***	0.80	5.40***	0.72	3.07***	0.46	1.06***	0.28
Covariance (mean and discrepancy)	0.07	0.17	-0.66**	0.31	0.55*	0.27	-0.20	0.19	-0.70***	0.15
-2 log likelihood	1,498.5		1,690.1		1,653.4		1,513.8		1,387.4	

Notes: Dyad *N* = 266. Observations *N* = 397–400. IWD = individual with dementia; MMSE = Mini-Mental State Examination.

^aNegative discrepancy scores indicate that the caregiver is reporting more importance than IWD is reporting; Positive discrepancy scores indicate that the IWD is reporting more importance than the caregiver is reporting.

†*p* < .10; **p* < .05; ***p* < .01; ****p* < .001.

Discussion

The results of this study demonstrate that there are systematic discrepancies in perceived values of the IWD between IWDs’ self-reports and caregiver reports and that these discrepancies can be explained in part by caregivers’ beliefs about the IWD’s involvement in care decision making.

In response to the first hypothesis, we found that, as compared with IWD self-report, caregivers consistently attributed less importance to all five of the IWD’s values in care (autonomy, burden, control,

family, and safety). These results confirm previous research (Carpenter et al., 2006; McCullough et al., 1993), which demonstrated similar discrepancies in caregiver and care receiver reports. The present analysis, however, extends these previous findings by indicating that the discrepancy is in the same direction across a set of five values.

In response to the second hypothesis, the findings highlight that caregiver beliefs are significantly associated with discrepancy in report between caregivers and IWDs. The discrepancies on all five values are significantly associated with the

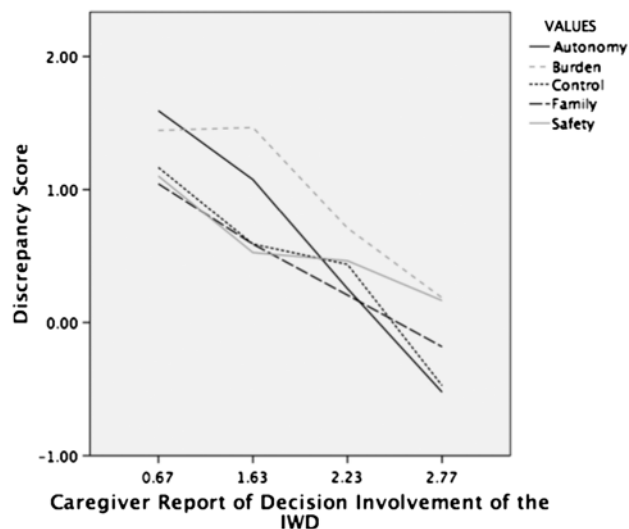


Figure 1. Discrepancy score as a function of caregiver report of perceived involvement of individual with dementia (IWD) in decision making. Negative discrepancy scores indicate that the caregiver is reporting more importance than the IWD is reporting, whereas positive discrepancy scores indicate that the IWD is reporting more importance than the caregiver is reporting. When caregivers report that their relative is more involved in decision making (higher score for perceived involvement of the IWD), then caregivers are more likely to have reported higher importance for that specified value than IWDs. When caregivers are reporting lower levels of involvement of the IWD in care decision making, then IWDs are more likely to report higher importance for the value than caregivers.

caregiver's interpretation of how involved the IWD is in making decisions about his/her own care and routine. When the caregiver reports greater behavioral involvement of the IWD in making decisions about care and routines (e.g., how to spend his/her own money or his/her own time and with whom), the caregiver also reports higher perceived importance of care values than held by the IWD. However, caregivers who see the IWD as less involved in making such decisions are more likely to report less perceived importance of the IWD's values than held by the IWD. The construct of decision involvement may arguably be a reflection of autonomy or values in general. However, it is distinct in asking for caregivers' observations about their relative's decision-making behavior in daily activities rather than the importance of specific values. Thus, what the caregiver believes to be true about the IWD's behaviors is associated with the discrepancy between his/her judgment of the IWD's values and the IWD's own report of his/her values. This finding may reflect the fact that IWDs who exercise more involvement in everyday decisions are more forthright in stating their values so that caregivers

have a better recognition of these values. It may also be that caregivers who support IWDs in making everyday decisions are more attuned to the IWD's values. By contrast, caregivers who view the IWD as less able to make everyday decisions may see that person as having greater impairment overall and thus attend less to the IWD's preferences. These findings of the relation of discrepancies to perceived involvement are consistent with dyadic coping theory. A breakdown in mutuality resulting in more apparent delegated coping strategies, reflected in this case by the caregiver's beliefs about the IWD's decision-making behaviors, may lead to misperceptions of the IWD's values and needs (Ledermann et al., 2010).

We cannot rule out the possibility that discrepancies in perceived values might be due in some ways to the IWD's cognitive difficulties. In response to rather than as a result of cognitive decline, IWDs may be reporting different values than they held in the past, but caregivers are not aware of this shift. Prior research, however, has found that IWD's statements about values and preferences are relatively stable, even as cognition declines (Feinberg & Whitlatch, 2001; Piiparinen, Tucke, & Whitlatch, 2008). Furthermore, discrepancies in the present study were not associated with cognitive functioning except in two instances. First, for the value of burden, IWDs with higher MMSE scores were more likely to place more importance on avoiding being a burden than their caregiver thought they did. Second, as noted, for dyads with a non-African American caregiver, IWDs with higher MMSE scores were less likely to place importance on the value of autonomy as compared with their caregivers, whereas there was no significant association for dyads with an African American caregiver. Taken together, these findings suggest no consistent effects of cognitive impairment on discrepancies.

Additionally, we found that caregiver race is significantly associated with discrepancy in report on the values of control and safety. In both instances, African American caregivers are more likely to report greater perceived importance of the value for IWDs than the IWD's self-report. This higher report by African American caregivers may reflect a cultural difference in interpreting values and preferences in care. There is some evidence that African American caregivers experience lower levels of emotional distress than White caregivers (e.g., Roth, Haley, Owen, Clay, & Goode, 2001), which may affect how these individuals perceive their care

receiver's values. This finding may also reflect differing importance placed on control and safety in care, or in the way various racial and ethnic groups respond to end-of-life decision making, as found by Schmid, Allen, Haley, and DeCoster (2010).

Surprisingly, neither caregivers' ratings of the importance of taking the IWD's best interests into account nor dyadic strain was related to discrepancies. Caregivers' responses on the best interests scale may reflect widely held social norms that they should take the IWD's interests into account, and they may fully intend to do so. Nonetheless, without fully understanding the IWD's values, they may not be able to make choices that reflect the IWD's preferences. The lack of association of discrepancies and dyadic strain underscores that understanding the other person's values is distinct from the amount of tension or conflict in a relationship. These findings suggest that dyadic strain should not be viewed as the sole indicator of a caregiver's ability to serve as a substitute decision maker.

Even though values and preferences may remain stable with advancing dementia, IWDs are likely to become less involved in decision making over time (Menne & Whitlatch, 2007). As a result, caregivers may become increasingly incongruent in recognizing the IWD's values and preferences. They may discount the IWD's preferences because of his/her cognitive impairment or stop listening to the IWD as they become overburdened and overstressed. By contrast, interventions early in the disease process could help caregivers gain a firmer understanding of the IWD's wishes that is less amenable to perceptions of daily involvement in care. These interventions could also empower caregivers to make difficult decisions later on in the disease, such as using respite care, placement in a nursing home, or end-of-life decisions, because they know it is what the IWD would want.

State and federal policies have increasingly encouraged family members of older people to take on the role of health care proxy in the event of reduced decisional capacity. A New York State program, Medical Orders for Life Sustaining Treatment, goes beyond typical advance directives by outlining in detail for surrogates a patient's preferences for end-of-life care (New York State Department of Health, 2010). A similar approach in the early stages of dementia could encourage assessment of IWD's values and preferences for daily care decision making and guide professionals and families who take on the role of surrogate

decision maker. A combination of assessment and interventions with families, or other potential surrogates, may be helpful in improving understanding of an older person's values. It should be noted, however, that brief discussions might not be enough to improve understanding of care preferences (Ditto et al., 2001). Rather, values appear to be complex, and to understand a person's values, it may require an in-depth culturally sensitive technique that assesses values and preferences, considers the caregiver's beliefs about care, and seeks to improve communication within the dyad in the early stages of dementia. These interventions could institute a person-centered approach to care as well as lower caregiver stress and guilt in the decision-making process.

The current study has some limitations. First, although the sample was strengthened by its racial diversity, we used a sample of convenience, and findings may not be generalizable to all IWDs and caregivers. Second, findings may not extend to individuals with more severe dementia. As dementia progresses, IWDs will be less able to indicate in a clear way their preferences about care (Elliott et al., 2009). This finding, however, underscores the importance of early interventions. Third, the factors associated with discrepancies in values in this study only account for a portion of the variance to be explained. Other factors, not considered in these analyses (e.g., intensity of care provided, activity of daily living or instrumental activity of daily living functional impairment, and IWD level of education) may be more salient indicators of discrepancies. Fourth, this study focused only on discrepancies in values, yet much could be learned by examining discordance in the dyad on other issues (e.g., engaging in social or other activities). Fifth, discordance in values may be a time-sensitive construct. In the present study, we are not able to determine if discrepancies arose in response to cognitive impairment or were long standing. Sixth, the results are limited by the model fit of the factor structures for caregivers and IWDs as analyses only demonstrated adequate fit. Lastly, the findings are cross-sectional, and we cannot make assumptions about which came first, the discrepancies or the caregivers' beliefs. Longitudinal examination of these values would give a clearer depiction of preceding factors to the discrepancy as well as consequential outcomes of such discrepancies.

Despite such limitations, this study is one of few to consider the caregiving relationship as a dyadic

process and to investigate factors associated with discrepant views of IWDs' values and preferences in care. A next research step is determining the consequences or risks of discrepancies for quality of life or well-being. A next practical step is to develop and evaluate protocols for improving assessment and communication within dyads to ensure that medical and social decisions are made in such a way that they reflect the IWD's actual values. These interventions, if conducted early in the IWD's illness, could provide a foundation that helps family members, and other care providers, more effectively meet the challenges that lie ahead and maximize the quality of life for both the IWD and caregiver.

Funding

This work was supported by grants from the Administration on Aging (grant number 90CG2566), the Robert Wood Johnson Foundation, the AARP Andrus Foundation, the Retirement Research Foundation, the National Institute of Aging (grant number P50 AG08012), and the National Institute of Mental Health (grant number R01070629).

Acknowledgments

The authors would like to extend their appreciation to the staff members of the Margaret Blenkner Research Institute who have worked on the dyad research team and to the families who participated in this study.

References

Baldwin, C. (2005). Narrative, ethics and people with severe mental illness. *Australian and New Zealand Journal of Psychiatry*, 39, 1022–1029.

Bass, D. M., Tausig, M. B., & Noelker, L. S. (1989). Elder impairment, social support, and caregiver strain: A framework for understanding support's effects. *Journal of Applied Social Sciences*, 13, 80–115.

Berg, C. A., & Upchurch, R. (2007). A developmental-contextual model of couples coping with chronic illness across the adult life span. *Psychological Bulletin*, 133, 920–954. doi:10.1037/0033-2909.133.6.920.

Bodenmann, G. (1995). A systemic-transactional conceptualization of stress and coping in couples. *Swiss Journal of Psychology*, 54, 34–49.

Bryk, A. S., & Raudenbush, S. W. (1992). *Hierarchical linear models*. Newbury Park, CA: Sage.

Carpenter, B. D., Lee, M., Ruckdeschel, K., van Hantsma, K. S., & Feldman, P. H. (2006). Adult children as informants about parent's psychosocial preferences. *Family Relations*, 55, 552–563.

Clark, P. A., Tucke, S. S., & Whitlatch, C. J. (2008). Consistency of information from persons with dementia: An analysis of differences by question type. *Dementia*, 7, 341–358. doi:10.1177/1471301208093288.

Crespo, M., López, J., & Zarit, S. H. (2005). Depression and anxiety in primary caregivers: A comparative study of caregivers of demented and non-demented older persons. *International Journal of Geriatric Psychiatry*, 20, 591–592. doi:10.1002/gps.1321.

Ditto, P. H., Hanks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., Dresser, R., et al. (2001). Advance directives as acts of communication. *Archives of Internal Medicine*, 161, 421–430.

Downs, M., Small, N., & Froggatt, K. (2006). Person-centered care for people with severe dementia. In A. Burns, & B. Winblad (Eds.), *Severe dementia* (pp. 193–204). West Sussex, UK: John Wiley & Sons, Ltd.

Elliott, B. A., Gessert, C. E., & Peden-McAlpine, C. (2009). Family decision-making in advanced dementia: Narrative and ethics. *Scandinavian Journal of Caring Sciences*, 23, 251–258. doi:10.1111/j.1471-6712.2008.00613.x.

Fagerlin, A., Ditto, P. H., Hawkins, N. A., Schnieder, C. E., & Smucker, W. D. (2002). The use of advance directives in end-of-life decision making: Problems and possibilities. *American Behavioral Scientist*, 46, 268–283. doi:10.1177/0002764202046002007.

Feinberg, L. F., & Whitlatch, C. J. (2001). Are persons with cognitive impairment able to state consistent choices? *The Gerontologist*, 41, 374–382.

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.

Karel, M. J., Moye, J., Bank, A., & Azar, A. R. (2007). Three methods of assessing values for advance care planning: Comparing persons with and without dementia. *Journal of Aging and Health*, 19, 123–151. doi:10.1177/0898264306296394.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.

Ledermann, T., Bodenmann, G., Gagliardi, S., Charvos, L., Verardi, S., Rossier, J., et al. (2010). Psychometrics of the dyadic coping inventory in three language groups. *Swiss Journal of Psychology*, 69, 201–212. doi:10.1024/1421-0185/a000024.

Littell, R. C., Milliken, G. A., Stroup, W. W., & Wolfinger, R. D. (1996). *SAS system for mixed models*. Cary, NC: SAS Institute.

Lyons, K. S., Zarit, S. H., Sayer, A. G., & Whitlatch, C. J. (2002). Caregiving as a dyadic process: Perspectives from caregiver and receiver. *Journal of Gerontology*, 57B, 195–204.

Maguire, M. C. (1999). Treating the dyad as the unit of analysis: A primer on three analytic approaches. *Journal of Marriage and the Family*, 61, 213–223.

Martire, L. M., Schulz, R., Reynolds, C. F., Morse, J. Q., Butters, M. A., & Hinrichsen, G. A. (2008). Impact of close family members on older adults' early response to depression treatment. *Psychology and Aging*, 23, 447–452. doi:10.1037/0882-7974.23.2.447.

McCullough, L. B., Wilson, N. L., Teasdale, T. A., Kolpakchi, A. L., & Skelly, J. R. (1993). Mapping personal, familial, and professional values in long-term care decisions. *The Gerontologist*, 33, 324–332.

Menne, H. L., Tucke, S. S., Whitlatch, C. J., & Feinberg, L. F. (2008). Decision-making involvement scale for individuals with dementia and family caregivers. *American Journal of Alzheimer's Disease and Other Dementias*, 23, 23–29. doi:10.1177/1533317507308312.

Menne, H. L., & Whitlatch, C. J. (2007). Decision-making involvement of individuals with dementia. *The Gerontologist*, 47, 810–819.

Meyler, D., Stimpson, J. P., & Peek, M. K. (2007). Health concordance within couples: A systematic review. *Social Science and Medicine*, 64, 2297–2310. doi:10.1016/j.socscimed.2007.02.007.

New York State Department of Health. (2010). *Medical orders for life sustaining treatment (MOLST)*. Retrieved from http://www.health.state.ny.us/professionals/patients/patient_rights/molst/

Piiparinen, R. P., Tucke, S., & Whitlatch, C. J. (2008, April). *Everyday care values and preferences within care dyads: Incongruence across time*. Presented at the annual meeting of the Ohio Association for Gerontology and Education, Cleveland, OH.

Roth, D. L., Haley, W. E., Owen, J. E., Clay, O. J., & Goode, K. T. (2001). Latent growth models of the longitudinal effects of dementia caregiving: A comparison of African American and White family caregivers. *Psychology and Aging*, 16, 427–436. doi:10.1037/0882-7974.16.3.427.

Schmid, B., Allen, R. S., Haley, P. P., & DeCoster, J. (2010). Family matters: Dyadic agreement in end-of-life medical decision making. *The Gerontologist*, 50, 226–237. doi:10.1093/geront/gnp166.

Schreiner, A. S., Morimoto, T., Arai, Y., & Zarit, S. (2006). Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden Interview. *Aging and Mental Health*, 10, 107–111. doi:10.1080/13607860500312142.

Sebern, M. D., & Whitlatch, C. J. (2007). Dyadic relationship scale: A measure of the impact of the provision and receipt of family care. *The Gerontologist*, 47, 741–751.

Whitlatch, C. J., & Feinberg, L. F. (2003). Planning for the future together in culturally diverse families: Making everyday care decisions. *Alzheimer's Care Quarterly*, 4, 51–61.

Whitlatch, C. J., Feinberg, L. F., & Tucke, S. (2005a). Accuracy and consistency of responses from persons with cognitive impairment. *Dementia*, 4, 171–183. doi:10.1177/1471301205051091.

Whitlatch, C. J., Feinberg, L. F., & Tucke, S. S. (2005b). 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., Piiparinen, R., & Feinberg, L. F. (2009). How well do family caregivers know their relatives' care values and preferences? *Dementia*, 8, 223–243. doi:10.1177/1471301209103259.
- Zarit, S. H., & Braungart, E. R. (2007). Elders as care receivers: Autonomy in the context of frailty. In H-W Wahl, C. Tesch-Romer, & A. Hoff (Eds.), *New dynamics in old age individual, environmental, and societal perspectives* (pp. 85–104). Amityville, NY: Baywood Publishing Company.
- Zarit, S. H., Femia, E. E., Kim, K., & Whitlatch, C. J. (2010). The structure of risk factors and outcomes for family caregivers: Implications for assessment and treatment. *Aging and Mental Health*, 14, 220–231.
- Zweibel, N., & Lydens, L. A. (1990). Incongruent perceptions of older adult/caregiver dyads. *Family Relations*, 39, 63–67.