

# Quality of Life for Dementia Caregiving Dyads: Effects of Incongruent Perceptions of Everyday Care and Values

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## Abstract

**Purpose of the Study:** This dyadic study investigated incongruence in care recipients' (CRs') and caregivers' (CGs') perceptions of (a) CRs' involvement in decision making and (b) how much CRs value social relations as predictors of subjective quality of life (QOL) of CRs with mild-to-moderate dementia and their primary family CGs.

**Design and Methods:** A secondary analysis of cross-sectional, dyadic data from in-person interviews with 205 CRs with mild-to-moderate dementia and their primary family CGs. Incongruence was operationalized in two ways: absolute difference and direction of difference. Paired *t* tests and multilevel modeling were used to analyze differences.

**Results:** CGs reported CRs were significantly less involved in decision making and valued social relations significantly less than CRs. Greater incongruence on CRs' values significantly predicted lower QOL of CG and CR. When CGs reported that CRs valued social relationships less than the CR himself/herself reported, CGs' and CRs' QOL was significantly lower compared with QOL for dyads where there was no incongruence on CRs' values. Incongruent perceptions of CRs' involvement in decisions were not a significant predictor of QOL.

**Implications:** This study provides evidence for the importance of assessing both CRs' and CGs' QOL, as well as incongruence in their perceptions in domains that may affect both of their QOL.

**Keywords:** Caregiving, Dyad, Mild-to-moderate dementia, Quality of life

This dyadic study focuses on care recipients (CRs) with mild-to-moderate dementia and their primary family caregiver (CG). The purpose was to investigate whether incongruent perceptions between CRs and CGs predict subjective quality of life (QOL) of both CRs and CGs. One in eight people aged 65 and older (5.4 million) suffer from Alzheimer's disease (AD), only one of several forms of dementia (Alzheimer's Association, 2015). Mild cognitive impairment (MCI), a symptomatic stage prior to dementia, is estimated to affect 16%–20% of older adults (Roberts & Knopman, 2013), although estimates vary widely (Gomersall et al., 2015). Individuals at a

mild-to-moderate stage of dementia can perform the functions of daily life despite noticeable decline in cognitive function (Alzheimer's Association, 2015), report on their experience (Menne & Whitlatch, 2007), express their preferences in decision making (Whitlatch, Feinberg, & Tucke, 2005; Whitlatch, Piiparinen, & Feinberg, 2009), and indicate their desire to be involved in decisions about their care (Horton-Deutsch, 2007). Thus, it seems logical that the perspectives of CRs with mild-to-moderate dementia should be solicited.

The perspectives of CRs with mild-to-moderate dementia should also be solicited because caregiving is inherently

a dyadic process. Unfortunately, perceptions of CRs with dementia tend to be overlooked. For instance, some family CGs make critical daily care decisions without an understanding of what their loved ones value (Menne & Whitlatch, 2007; Whitlatch et al., 2009); most research on dementia caregiving emphasizes the CGs' experience (Braun et al., 2009), with the CRs' perspectives often downplayed or neglected; and, practitioners often make care plans without knowing the care values of the CR (Whitlatch et al., 2005). Failure to account for CRs' expectations or desires may threaten the CRs' self-esteem, sense of control, autonomy, physical and psychological health (Brown, 2007) or sense of self (Gomersall et al., 2015), and the amount of caregiving the CG assumes because of misunderstandings about a CRs' preference and capability eventually adds extra stress to the CGs' life (Horowitz, Goodman, & Reinhardt, 2004; Whitlatch et al., 2009).

### **Prior Evidence About Incongruence Between Dementia CGs and CRs**

Prior caregiving studies have explored incongruence between CG and CR but vary widely in the type of incongruence examined and the sample. There is evidence, for example, of incongruence between frail elderly CRs with cancer and CGs regarding CRs' symptoms and distress (e.g., Riley-Doucet, 2005), end-stage renal disease patients and their spouse CGs regarding the patients' QOL (e.g., Ferri & Pruchno, 2009), and frail older adults with functional impairment and their CGs regarding CRs' competence (e.g., Horowitz, et al., 2004). However, less is known about incongruence between CRs with mild-to-moderate dementia and their CGs.

The present study examined incongruence in CGs' and CRs' reports of the CRs' involvement in decisions about day-to-day care and how much the CR values social relations. Despite a large number of dimensions on which incongruence between CGs and CRs could be measured, prior studies have most often examined incongruent perceptions about the ability of elderly dementia patients to make decisions about medical treatment or advanced directives (Menne et al., 2008). There has been less focus on incongruent perceptions about dementia CRs' involvement with day-to-day care decisions such as choice of food, clothes, and leisure activity. One exception is research by Feinberg and Whitlatch (2002), which found CRs thought that they participated more in day-to-day care decisions than CGs reported.

Values and preferences underlying dementia caregiving decisions are another important domain in which to consider CR-CG incongruence (Whitlatch et al., 2009). Whitlatch and colleagues (2009) showed CG and CR agreement in perceptions of CRs' preferences in health care, finances, personal care, social activities, living arrangement, and possible nursing home placement, but disagreement on CRs' preferences in choosing informal and formal care

providers and who would take responsibility for specific daily activities (i.e., shopping, bathing). Reamy, Kim, Zarit, and Whitlatch (2011) reported that CGs perceive CRs' values about autonomy, burden, control, continuity of social relationships, family, and safety as being less important than CRs reported.

### **Prior Evidence About QOL in Dementia CGs and CRs**

There is a large literature investigating QOL for CGs of individuals with dementia. Deterioration in dementia CGs' physical health, psychological well-being, and social relations has been well documented (review by Sørensen & Conwell, 2011). Compared with other CGs, they tend to have worse mental and physical health, less leisure time, more employment complications, and more family conflict (e.g., Bertrand, Fredman, & Saczynski, 2006; Moon & Dilworth-Anderson, 2015). A smaller literature on QOL in CGs of individuals with MCI has also found evidence of adverse effects on CGs' QOL (Blieszner and Roberto, 2010; Springate & Tremont, 2013).

QOL in individuals with dementia has been less well studied than for their CGs. Lawton (1997) was the first to emphasize the importance of getting information about QOL of CRs with dementia, and QOL has been increasingly recognized as an important outcome to measure for both CGs and CRs in the dementia context (Selwood, Thorgrimsen, & Orrell, 2005). A growing number of measures are being developed to assess QOL in dementia populations (Ready & Ott, 2003). Still, a review by Naglie (2007) concluded that QOL was rarely included as a primary outcome for CRs with dementia, although it was included in some studies as a secondary outcome to assess whether interventions or treatment for dementia patients made a clinically significant difference. Research on how CRs with mild-to-moderate dementia, specifically, perceive their QOL is very limited. Carpenter, Kissel, and Lee (2007) reported evidence that QOL reports were just as reliable in individuals with mild dementia as in individuals with very mild or no dementia. The current study responded to the limited research on QOL of CRs with mild-to-moderate dementia, especially research including QOL of both CRs and CGs. The present study drew upon Logsdon, Gibbons, McCurry, and Teri (1999, 2005) research to define QOL broadly, for both CRs and CGs, as their assessment of their physical health, psychological state, social relationships, and environment.

### **Theoretical Basis for Hypothesizing a Relationship Between Incongruence and QOL**

The present study hypothesizes that incongruence in CRs' and CGs' perceptions will be a significant predictor of CRs' and CGs' QOL. Antonucci and Israel (1986) suggested, hypothetically, that incongruence in CGs' and CRs' perceptions of the importance of various day-to-day care

tasks may influence the QOL of CGs and CRs, but empirical evidence in dementia caregiving research for the effect of incongruence on caregiving outcomes is lacking (Lyons, Zarit, Sayer, & Whitlatch, 2002). We know of no prior studies that have examined the impact of incongruence on QOL of CGs and CRs with mild-to-moderate dementia.

A theoretical basis for hypothesizing incongruence would be related to QOL comes from Interdependence Theory (IT; Kelley & Thibaut, 1978). IT provides a framework for understanding dynamics of interaction and interconnectedness of outcomes in dyads, along with the dispositional and contextual factors associated with different patterns of interdependence. A key idea is that individuals in dyads influence each other not only directly, but also through joint decisions or attributes (Kelley & Thibaut, 1978; Kelley et al., 2003).

Applying IT to caregiving of individuals with mild-to-moderate dementia, our study assumes that caregiving will proceed less smoothly and will be less mutually rewarding when the CR and CG do not share common perceptions about the CRs' capabilities, needs, and values. Although dyadic incongruence can be conceptualized in many ways (Thompson & Walker, 1982), our study focuses specifically on discrepancy between CGs' and CRs' reports of the CRs' (a) decision-making involvement (DMI) and (b) values related to social relationships. Based on IT, dyadic incongruence should be associated with poorer well-being (defined here as lower QOL). Including the QOL of both CRs and CGs acknowledges that caregiving is a dyadic process and allows for interdependence in the outcome.

Our study investigates two aspects of incongruence: magnitude and direction. To our knowledge, ours is the first study in dementia caregiving to examine both. Magnitude captures the degree to which CRs' report of her/his DMI and values for social relations and CGs' report of CR's DMI and values for social relations diverge. Magnitude of incongruence reveals varying gradations of disagreement and/or extreme scores within families (Davis, 1993). In IT, greater divergence in partners' affect, cognition, motivation or behavior would be expected to reduce the dyad's ability to construct a common "interpersonal reality" (Rusbult & Van Lange, 2003, p. 353). As a result, dyadic interaction becomes less predictable, the outcome of an interaction becomes less mutually satisfying, and it becomes more likely that at least one person's needs would be frustrated (Kelley & Thibaut, 1978). This should be reflected in lower QOL for one or both partners. Differences in magnitude may identify dyads most in need of intervention to bring perceptions into better alignment and achieve mutually satisfying outcomes (Horowitz et al., 2004).

Direction captures a different aspect of discrepancy, namely which partner thinks the CR has greater DMI or places greater value on social relations. Imbalance in levels of dependence (i.e., power differences), lower mutuality of dependence, or lack of covariation of interests between partners (Rusbult & Van Lange, 2003) may be uncovered

by the direction of differences. Direction also may be useful in identifying systematic patterns of discrepancy for further study into their causes or designing more effective dyadic interventions. The value of considering both magnitude and direction is that various patterns can be revealed: for example, a CG may report lower decision-making involvement of the CR than the CR reports but the discrepancy may be small or large.

Our study controlled for CGs' and CRs' report of relationship strain, CG and CR race, CRs' activities of daily living (ADL) limitations, CGs' perceived income adequacy, CGs' gender, and kin relationship of CG to CR. These covariates were included because of their associations with QOL in prior caregiving research. Relationship strain was included specifically to control for the possibility that greater incongruence might be associated with greater strain. According to IT (Kelley et al., 2003), interactions that fail to satisfy important needs and preferences or are asymmetrical with regard to dependence will be associated with a more negative interpersonal relationship.

## Research Questions and Hypotheses

This study posed three research questions (RQs) and hypotheses (Hs).

- (RQ1) Is there significant incongruence between CGs and CRs in perceptions of (a) CRs' DMI and (b) CRs' values about social relations? If yes, what is the direction of the difference? Significant incongruence was expected, based on prior studies, even though those studies have rarely investigated incongruence in these specific domains or with CRs with mild-to-moderate dementia. Also based on prior studies, we hypothesized that CGs will report lower involvement of CRs in decision making (H1) and lower value placed by CR on social relationships (H2) than CRs' report.
- (RQ2) Does greater incongruence predict worse QOL? We hypothesized that more incongruence between CGs and CRs in their perceptions of CRs' decision-making involvement and values will predict worse QOL (H3).
- (RQ3) Does the relationship between incongruence and QOL differ if incongruence is operationalized as direction of difference instead of magnitude of difference?

## Design and Methods

### Design and Sample

The study was based on a secondary analysis of the first wave of data from 205 dyads of community-dwelling CRs with mild-to-moderate dementia and their primary family CGs, recruited from client lists of the Family Caregiver Alliance in San Francisco, the Eldercare Services Institute

of the Benjamin Rose Institute in Cleveland, and the University Memory and Aging Center of Case Western Reserve University and University Hospitals in Cleveland. Inclusion criteria at the initial screening were CRs have a confirmed diagnosis of a dementing condition or symptoms consistent with dementia and a Mini-Mental State Exam score between 13 and 26; live at home at the time of first interview; have a family CG who was providing the most hands-on assistance for the CR (see [Feinberg & Whitlatch, 2002](#), for details). Data were collected through separate in-person interviews with the CG and CR.

## Measures

Following the typology of [Kenny, Kashy, and Cook \(2006\)](#), we used a mix of within-dyad measures (where the CR and the CG have individual scores but the average score does not vary across dyads), mixed measures (where scores can vary both within and between dyads), and between-dyad measures (where a single score represents the dyad).

### Outcome (mixed measure)

The 13-item Quality of Life-Alzheimer's Disease (QOL-AD) Scale developed by [Logsdon and colleagues \(1999\)](#) was used to assess QOL. CRs reported their QOL and CGs reported their own QOL. The QOL-AD has been shown to be reliable and valid for both CRs with dementia ([Logsdon, Gibbons, McCurry, & Teri, 2002](#)) and CGs ([Logsdon et al., 2005](#)). Using response categories from 1 (*poor*) to 4 (*excellent*), the QOL-AD assessed the CGs' or CRs' physical health (e.g., how do you feel about your physical health?), psychological health (e.g., How has your mood been lately?), interpersonal relationships (e.g., How would you describe your current relationship with your friends?), and environment (e.g., How do you feel about the place you live now?). Total scores can range from 13 to 52. Higher scores indicate better QOL (CG  $\alpha = .88$ , CR  $\alpha = .85$ ).

### Predictors (between-dyads measures)

CR DMI was measured by 14 items from the DMI scale ([Feinberg & Whitlatch, 2002](#)). The DMI was adapted from the Decision Control Inventory developed by [Conroy and Yuskas \(1996\)](#). The DMI assesses how much the CR reports himself/herself to be involved in various decisions (e.g., when to get up) and how much the CG thinks the CR is involved in making the same decisions (from 0 (*not involved at all*) to 3 (*very involved*). Possible range of DMI scores is from 0 to 42, higher scores indicating higher reported CR involvement in decision making (CG  $\alpha = .92$ , CR  $\alpha = .84$ ).

A 5-item Social Relations Values subscale (VALUES), part of a 24-item Care Values and Preferences Scale developed by [Whitlatch and colleagues \(2009\)](#), was used to assess the importance CR places on social relations (e.g., Be with family/friends), as well as the CGs' perception of the CRs' values about social relations, from 1 (*not at all important*)

to 3 (*very important*). Possible range on the VALUES scale is 5–15, higher scores indicating a greater perceived importance of social relations for CR (CG  $\alpha = .75$ , CR  $\alpha = .60$ ).

### Operationalization of Incongruence

Incongruence between CG and CR regarding DMI and VALUES was operationalized in two different ways: (i) absolute difference (ICG score – CR score) and (ii) direction of difference. To represent direction, two dummy variables were created for each incongruence measure (DMI or VALUES): the first was coded 1 if the CGs' answer was higher than the CRs' answer, otherwise 0; and the second was coded 1 if the CRs' answer was higher than the CGs' answer, otherwise 0. Consequently, the reference group was dyads in which there was no difference in perceptions. In the absence of criteria for defining congruence (i.e., no difference), we took the most conservative approach.

### Covariates (within-dyads or mixed measures)

To identify who the respondent was (within dyads), an indicator was coded  $-.5 = \text{CG}$  or  $.5 = \text{CR}$ . CGs' and CRs' race (within dyads) was coded 1 = White or 0 = non-White. Relationship strain (a mixed measure) was assessed by a 4-item subscale (Relationship Strain) of a 9-item Dyadic Relationship Scale originally developed by [Poulshock and Deimling \(1984\)](#). The four items were selected because they asked specifically about the CG and CR relationship (e.g., I felt angry toward her/him). The CG and CR each reported their own perception of relationship strain from 0 (*strongly disagree*) to 3 (*strongly agree*). Total scores could range from 0 to 12, and higher scores indicate more strain with the CG or CR (CG  $\alpha = .91$ , CR  $\alpha = .87$ ). In multilevel analysis, relationship strain was centered around the mean for CGs or CRs, respectively, to improve interpretability of the intercept.

### Covariates (between-dyads measures)

Gender of CG is coded 0 (*male*) or 1 (*female*). CG kin relationship to the CR was coded 1 (*simply spouse*) or 0 (*non-spouse*) because of too few cases to draw distinctions within the non-spouse category. For income adequacy, CGs were asked "Do you have enough money for basic needs?" (0 = *strongly disagree* to 3 = *strongly agree*). CGs' report of CRs' functioning on the Katz Index of ADL ([Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963](#)) was included. CGs reported whether CRs often had problems (0 = *no*, 1 = *yes*) with four ADL (dressing, bathing, toileting, and eating). Total ADL scores could range from 0 to 4, higher scores indicating greater ADL impairment.

## Analysis Plan

### Paired t Tests

A two-tailed paired *t* test at  $\alpha < .05$  was used to analyze differences between CGs and CRs in CR's DMI and VALUES, by subtracting the CRs' score on each measure from the



matching CGs' score. This answered RQ1, whether there was a significant mean difference between CGs and CRs in perceptions of CRs' involvement on decision making (H1) and CRs' values about social relations (H2).

### Multilevel Modeling

We expected the outcome (CR and CG QOL), which is assumed to be a product of the interaction between the two individuals, would be interdependent. Consequently, for the multivariate dyadic analyses, we used HLM6 software (Raudenbush, Bryk, & Congdon, 2004) to estimate a two-level (individuals nested within dyads) random intercept multilevel modeling (MLM) (corresponding to the standard reciprocal model in Kenny et al., 2006). Given the cross-sectional design and only two partners in a dyad, the maximum number of random effects that can be specified is one. MLM assumes that residuals are random variables with means equal to zero and variance  $\sigma^2$  at Level 1 and  $\tau_{00}$  at Level 2. The random variables are assumed to be normally distributed.

The outcome ( $Y_{ij}$ ) is the predicted QOL for individual  $i$  (i.e., CG or CR) in dyad  $j$ . Predictors and covariates were entered in Level 1 if they were within-dyad or mixed measures (CG/CR indicator, relationship strain, race) or in Level 2 if they were between-dyads measures (DMI and VALUES incongruence, female CG, spouse CG, CG income adequacy, CR ADL). The intraclass correlation (ICC) was calculated to assess whether QOL is correlated between CGs and CRs, justifying MLM. Full Information Maximum Likelihood estimation (Bryk & Raudenbush, 1992) was used because only cases with complete data were analyzed. Change in deviance was used to assess improvement in model fit when more parameters were added to a model (Raudenbush & Bryk, 2002). An alternative approach to modeling cross-sectional dyadic data, a dual-intercepts or multivariate outcomes model (Kenny et al., 2006; Sayer & Klute, 2005), was not implemented because creation of parallel measures of QOL with equal true scores, variances, reliabilities, and domain content (Nunnally & Bernstein, 1994) was not feasible in our study and our research questions focused on dyadic-level incongruence rather than actor-partner effects.

Three nested models were tested. Model 1 contained only the indicator for respondent ( $-.5 = \text{CG}$  or  $+.5 = \text{CR}$ ). Model 2 added all covariates (within-dyad and mixed at Level 1 and between dyads at Level 2). Model 3 varied depending on whether the absolute difference in DMI and VALUES were added (Model 3a) or the direction of differences in DMI and VALUES (Model 3b). Model 3a tested H3 (RQ2), and results in Models 3a and 3b were compared with answer RQ3.

Equations for the final model (version 3a) were as follows:

$$\text{Level 1 (within dyad): } Y_{ij} = \beta_{0j} + \beta_{1j} (\text{respondent}) + \beta_{2j} (\text{relationship strain}) + \beta_{3j} (\text{race}) + e_{ij}$$

$$\text{Level 2 (between dyads): } \beta_{0j} = \gamma_{00} + \gamma_{01}\omega_{1j} + \gamma_{02}\omega_{2j} + \gamma_{03}\omega_{3j} + \gamma_{04}\omega_{4j} + \gamma_{05}\omega_{5j} + \gamma_{06}\omega_{6j} + u_{0j}$$

$$\beta_{1j} = \gamma_{10}$$

$$\beta_{2j} = \gamma_{20}$$

$$\beta_{3j} = \gamma_{30}$$

## Results

### Demographic Description of the Sample

As seen in Table 1, the average CG was in her or his early 60s, but there was a large age range, and the majority of CGs were White (60%) and women (79%). The majority of CGs of color were African American. Average level of CGs' education was college graduate and, on average, CGs agreed that their income was adequate. Slightly more than half of CGs (55%) were spouses, primarily wives caring for husbands (75% of spouses). In the non-spouse CG group, most were daughters (64%). Average age of CRs was mid-70s but, like CG age, there was a broad range. Like the CGs, most CRs (58%) were White. Average level of CRs' education was some college. Consistent with their mild-to-moderate level of dementia, CRs were reported to have a relatively low mean level of ADL limitation. Alzheimer's disease was the most common diagnosis ( $n = 87$ , 42.44%), while 1 in 10 CRs had no diagnosis (not shown in Table 1).

**Table 1.** Demographic Characteristics of Caregivers and Care Recipients

Characteristic	M (SD)
Caregivers (N = 205)	
Age	
30–91 years	62.49 (13.44)
Gender (1 = Female)	0.79 (0.41)
Race (1 = White)	0.60 (0.49)
Education	4.16 (1.21)
Income adequacy	2.21 (0.52)
Kin relationship to CR (1 = Spouse)	0.55 (0.50)
Number of months caregiver has provided care	
1–265 months	36.36 (0.39)
ADL	1.05 (1.06)
Care recipients (N = 205)	
Age	
39–97 years	75.98 (9.24)
Race (1 = White)	0.58 (0.49)
Education	3.59 (1.49)

Notes. Education was coded as follows: 0 = less than high school, 1 = some high school, 2 = high school graduate, 3 = some college, 4 = college graduate, 5 = postgraduate degree. Income adequacy was coded as follows: 0 = strongly disagree, 1 = disagree, 2 = agree, 3 = strongly agree. ADL = activities of daily living; CR = care recipient.

## Incongruence in Perceptions of CRs' Involvement in Decisions and Values

For DMI, both CGs ( $M = 26.64$ ,  $SD = 10.36$ ) and CRs ( $M = 33.33$ ,  $SD = 7.02$ ) reported a moderate level of DMI for the CR on average, but there was a wide range (0–42). CGs' report of the CRs' level of DMI was approximately 6 points lower, on average, than CRs' report. As hypothesized (H1), this was a statistically significant difference, paired  $t(204) = -9.36$ ,  $p < .01$ . Ignoring direction, the mean absolute difference on DMI was moderate ( $M = 12.85$ ,  $SD = 7.38$ ), but the magnitude of disagreement varied substantially across dyads, from 0 to 35.49.

The direction of difference in DMI indicated that 65% of dyads had CGs who thought CRs were less involved in decision making than CRs thought. One quarter (25%) of dyads had CGs who thought CRs were more involved in decision making than CRs thought. The remaining 9% of dyads showed no difference on CR DMI.

For VALUES, both CGs ( $M = 12.13$ ,  $SD = 2.43$ ) and CRs ( $M = 12.51$ ,  $SD = 1.95$ ) reported a high level of importance of social relations for the CR, on average, but there was a wide range of scores (5–15). CGs' report of the

importance CRs placed on VALUES was lower, on average, than CRs' report, as hypothesized (H2), although the difference was smaller than for DMI: CGs reported 0.38 points lower, on average. Although small, this difference was statistically significant, paired  $t(204) = -2.10$ ,  $p < .01$ . In terms of absolute differences, the average absolute difference was smaller ( $M = 2.61$ ,  $SD = 2.00$ ) on VALUES than on DMI, with absolute differences across dyads ranging from 0 to 7.

The direction of difference in VALUES revealed that 44% of dyads had CGs reporting a lower importance rating for CRs' involvement in social relations than CRs did. Just more than one third (34%) of dyads had CGs reporting a higher value on social relations for CRs than the CR reported. The remaining 21% of dyads showed no difference.

## Multilevel Results

As displayed in Table 2, average estimated QOL across respondents and dyads was 37.84 (intercept in Model 1). The average difference in QOL between CGs and CRs was

**Table 2.** Results From Multilevel Models Predicting CR and CG Quality of Life

	Model 1	Model 2	Absolute difference	Direction of difference
			Model 3a	Model 3b
Fixed effects				
Intercept	37.84 (0.34)	40.81*** (1.07)	41.00*** (1.15)	40.58*** (1.51)
Within dyads or mixed				
Respondent	-1.86** (0.56)	-2.29*** (0.55)	-2.28*** (0.55)	-2.28*** (0.55)
Relationship strain (centered)		-0.66*** (0.15)	-0.66*** (0.16)	-0.66*** (0.16)
Race			-0.42 (0.61)	-0.26 (0.62)
Between dyads				
Female CG		-1.89* (0.77)	-1.65* (0.77)	-1.69* (0.76)
Spouse CG		1.60** (0.66)	1.58** (0.65)	1.32* (0.65)
CG income adequacy (centered)		1.15 (0.62)	1.28* (0.60)	1.28* (0.60)
ADL		-1.10(0.30)***	-1.28** (0.32)	-1.22*** (0.30)
DMI (absolute difference)			-0.09 (0.05)	
VALUES (absolute difference)			-0.46* (0.18)	
DMI CG < CR				-0.51 (1.16)
DMI CG > CR				1.65 (1.06)
VALUES CG > CR				-0.43 (0.84)
VALUES CG < CR				-1.45* (0.78)
Variance components				
Between dyads ( $\tau_{00}$ )	7.80**	5.12***	4.39***	4.00***
Within dyads ( $\sigma^2$ )	31.15	28.50	28.50	28.52
Model fit statistics				
Deviance	2,565.93	2,511.21	2,503.65	24,699.73
Number of parameters	4	10	12	14
Chi square	297.08***	269.18***	259.02*	223.67***
Degrees of freedom	204	198	196	194

Notes. Respondent was coded as follows: -.5 = CG or .5 = CR. For Model 3b, CG = CR is the reference group for DMI and VALUES;  $\Delta$  Deviance indicates whether model fit is improved significantly.  $N = 205$  dyads, 410 observations.

ADL = activities of daily living; CG = caregiver; CR = care recipient; DMI = decision-making involvement.

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

-1.86 points, a significant difference. The negative direction indicates lower QOL in CRs than CGs. Model 1 showed much more unexplained variance in QOL within dyads ( $\sigma^2 = 31.15$ ) than between dyads ( $\tau_{00} = 7.80$ ), but the variability in QOL between dyads was statistically significant. Therefore, it was worthwhile to add predictors to explain both the within-dyad variance and the between-dyads variance. The ICC was .20, justifying multilevel modeling and confirming interdependence of CG and CR QOL. After adding within-dyad, mixed, and between-dyads covariates (Model 2), the estimated difference in QOL between CGs and CR was -2.29 points, a significant difference. Adding covariates (Model 2) significantly improved model fit compared with Model 1.

### Incongruence Operationalized With Absolute Differences

As hypothesized (H3), there was a significant effect of VALUES incongruence on QOL (Model 3a). Respondents in dyads who had more VALUES incongruence reported worse QOL; every one point higher in VALUES incongruence was associated with 0.46 points lower QOL, on average and all else equal. However, contrary to H3, DMI incongruence was not a significant predictor of QOL. Model 3a provided a significant improvement in fit over Model 2.

### Incongruence Operationalized as Direction of Differences

The last research question investigated the difference in multilevel results when incongruence was operationalized as direction of differences. As shown in Table 2, a significant association was found between QOL and one direction of difference on VALUES. When CGs report that the CRs value social relationships less than the CRs themselves report, QOL is 1.45 points lower, on average and all else equal. This provides evidence that both absolute incongruence on VALUES and a particular direction of incongruence on VALUES predict QOL (RQ3). As with DMI absolute difference, direction of difference on DMI was not significantly related to QOL. A significant difference in QOL between CG and CR (lower QOL for CRs) was still found in Model 3b. Model 3b was also a significant improvement in fit over Model 2.

### Covariates and QOL

In addition to VALUES incongruence (Model 3a or Model 3b), some covariates were significant predictors of QOL. Higher than average relationship strain, higher CR ADL limitations, and being in a dyad with a female CG were associated with lower QOL. Being in a dyad with a spouse CG and higher income adequacy for the CG were associated with higher QOL.

## Discussion

Interdependence Theory (Kelley & Thibaut, 1978) and dyadic, multilevel modeling was applied to (i) examine the magnitude and nature of incongruence between CGs and CRs about CRs' values in regards to social relations (VALUES) and CRs' DMI using the absolute difference and the direction of difference and (ii) determine the influence of VALUES and DMI incongruence on QOL of CRs with mild-to-moderate dementia and their family CGs. Our results provide evidence that some CGs and CRs have significantly different perceptions about CRs' levels of involvement in decision making and CRs' values for social relations. The results showed that incongruence on VALUES, but not on DMI, predicted QOL, and both absolute incongruence and direction of difference in VALUES mattered.

The majority of dyads showed different perceptions on CRs' DMI and VALUES, although the magnitude of the incongruence tended to be small to moderate. On average, CGs reported CRs as having significantly less involvement in decision making and as placing significantly lower importance on the value of social relations than CRs reported. The findings support previous studies (e.g., Reamy et al., 2011) revealing statistically significant differences within dyads about CRs' perceptions. However, our findings of variability in direction of difference across dyads (e.g., 34% of CRs reported lower VALUES scores than CG reported for them) argue that direction of differences should be considered as well as mean differences. The different directions also support the importance of assessing both CGs' and CRs' perspectives.

The present study could not investigate reasons for the observed incongruence. It is possible that CGs may not understand CRs' preferences. Previous research has found that CGs are likely to report CRs' disabilities as being more significant than CRs (e.g., Lyons et al., 2002). Because CGs have knowledge about the disease process, they may make plans in anticipation of future problems (e.g., behavioral disturbances; Whitlatch, 2008). Or possibly CGs may already deal with these issues, and be more aware of the importance of these issues than the CRs. From the perspective of CRs with mild-to-moderate dementia, it is possible that as they experience the disease, their perspectives on their lives may change and may influence their expectations for their own care, daily routine, and social relations (Gomersall et al., 2015).

As hypothesized, more incongruence between CGs and CRs regarding the importance of social relations to the CR was significantly associated with worse QOL. When the direction of incongruence was considered, QOL was significantly lower if CGs reported that the CRs value social relationships less than the CRs themselves reported, compared with QOL when there was no incongruence on VALUES. Because no previous studies have focused on the relationship between incongruence in CRs' values about social relations and both CGs' and CRs' QOL, these findings add to the existing literature.

The need to sustain autonomy and independence by maintaining social contact and past pleasant activities may be important to CRs' QOL (e.g., [Gomersall et al., 2015](#)). CGs' belief that CRs' social relations are less meaningful than CRs report may reflect CGs' stereotypes about CRs with dementia ([Menne and Whitlatch, 2007](#)) or actual problematic experiences with CRs' social relations. As a consequence, CGs may restrict or neglect social activities ([Burgener & Twigg, 2002](#)).

On the other hand, incongruent perceptions of CRs' DMI were not a significant predictor of QOL. In this study, DMI included everyday activities such as what to spend money on and what to eat. However, considering the gradual progression of dementia, it is possible that DMI incongruence about everyday health issues—such as general health care, community-based long-term care—may be more critical at the early stage of dementia to the QOL of both CGs and CRs than decision making in general daily activities ([Carpenter et al., 2007](#)). Our findings suggest that relationship strain and background factors may have stronger influences on QOL than DMI incongruence at this stage of dementia.

## Implications

Our results have implications for practice and future research. First, practitioners should consider incorporating CRs' perspective when planning care instead of solely depending on the CGs' perspective. Practitioners may need to actively implement programs structured for both partners. Most dementia caregiving intervention has focused on the CGs' perception of the caregiving context (e.g., [Braun et al., 2009](#)) or ability to cope with symptoms of dementia (e.g., behavior problems, [Whitlatch, Judge, Zarit, & Femia, 2006](#)). Less attention has been paid to intervention directly with CRs. Recent studies suggest that dyadic intervention is feasible with CRs with mild-to-moderate dementia and has the potential to benefit CGs and CRs ([Whitlatch et al., 2006](#); [Zarit et al., 2004](#)). Our findings highlight two promising areas for dyadic intervention to improve CRs' and CGs' QOL: incongruence in perceptions of the importance of social relations to the CR and relationship strain between CR and CG.

Practitioners may use the findings in this study to examine their own possible biases about the capacity, preferences, and needs of individuals with mild-to-moderate dementia, or the potential bias about relying exclusively on the CGs' perspective ([Whitlatch et al., 2005](#)). The high alpha values on QOL and DMI for the CRs in our study support other evidence that CRs with early-stage dementia can report on their experiences ([Whitlatch et al., 2005](#)). Our findings also show that practitioners should pay attention to differences in QOL between CGs and CRs with dementia. QOL of dementia CRs has received less attention compared with QOL of their CGs (e.g., [Burgener & Twigg, 2002](#)). Thus, when practitioners assess their clients with mild-to-moderate dementia, they should ask about various aspects of

QOL such as physical and functional impairment, psychosocial well-being, task performance, and social environments ([Logsdon et al., 1999, 2002](#)).

Methodologically our results underscore the value of using two different methods of operationalizing differences between CGs and CRs: absolute magnitude and direction. It was evident that both magnitude and direction were important, at least for VALUES. At the same time, it was evident that some differences in direction (i.e., when the CG reported the CR valued social relations less than the CR reported) mattered more than others. For direction, we classified any difference greater than 0 as incongruence; future research should explore alternative ways of operationalizing incongruence.

CG and CR QOL were correlated, supporting our use of MLM to produce correct standard errors in the presence of correlated outcomes. MLM also allowed us to investigate the importance of within-dyad, mixed, and between-dyads predictors and provided evidence of significant variability in QOL both within and between dyads. Our results revealed that some dyads have higher and some have lower QOL from the average dyad, and some dyads have larger differences between CG and CR in their QOL than the average dyad. Our final models left unexplained variability in QOL both between and within dyads. Thus, further research should identify other individual and dyadic characteristics that can help to explain CGs' and CRs' QOL.

Finally, our results support application of IT when researching mild-to-moderate dementia caregiving. Whereas most research on caregiving has investigated individual-level predictors, one of our dyadic-level predictors, incongruence in perceptions about importance of CRs' social relations, was a significant predictor of QOL. In contrast to prior caregiving research that studied outcomes for CG and CR separately, the correlation we found in QOL between CG and CR also shows the importance of conceptualizing caregiving as a dyadic process and incorporating outcomes for both partners simultaneously.

## Limitations

Several limitations should be noted. First, a cross-sectional design precludes investigating changes in incongruence, QOL, or their relationship, or ascertaining the direction of causation between them. Second, the lack of parallel measures of QOL prevented use of a dual-intercepts or multivariate outcomes model ([Kenny et al., 2006](#); [Sayer & Klute, 2005](#)) that could investigate actor-partner differences within dyads. Third, participants were recruited from health and social service organizations rather than from the community or other sources, possibly resulting in a sample which may show different characteristics from the larger population of mild-to-moderate dementia CRs and family CGs. Fourth, in order to conserve statistical power, we controlled for only six covariates and covariates were specified only as main effects. We did not have



any available measures of CGs' subjective stress as others have. CGs' report of CRs' ADL impairment was used as a proxy. Fifth, small numbers within the non-White category (e.g., Asian, Hispanic, and others) meant we were unable to investigate ethnic/racial differences other than White versus non-White. For the same reason, we were unable to analyze CG kin differences other than spouse versus non-spouse.

## Conclusions

Despite limitations, our results contribute to current knowledge in several ways. Our results support the importance of taking a dyadic perspective when considering the dementia caregiving experience. Further, we found evidence that some CGs and CRs have significantly different perceptions about CRs' decision-making involvement and CRs' values about social relations. Another important finding is that the domain in which incongruence is measured (in our case, decision-making involvement or values) may differentially influence CGs' and CRs' QOL. Our results indicate that dyad-level characteristics as well as within-dyad characteristics predict QOL when MLM is applied. Our results also reflect the advantages of including absolute differences and direction of differences as alternative, but complementary, ways of investigating incongruence. Finally, this study adds to the small but growing body of research documenting the feasibility and desirability of including the perspectives of individuals with mild-to-moderate dementia.

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