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Incongruent perceptions of the care values of hospitalized persons with dementia: A pilot study of patient-family caregiver dyads

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Abstract

Objective—Many difficult decisions are made in the inpatient hospital setting regarding the daily care of persons with dementia (PWDs). Incongruent perceptions of the PWD's care values limit the family caregiver's ability to make surrogate decisions. The objectives of this pilot study were to describe and identify determinants of incongruent perceptions in the hospital setting.

Methods—Using multilevel modeling, we examined cross-sectional data collected from 42 PWD-family caregiver dyads.

Results—There was a significant amount of incongruence, on average, for all four subscales representing the PWD's care values: autonomy = -0.33 ($p < .001$); burden = $-.49$ ($p < .001$); safety/quality of care = $-.26$ ($p < .001$); and social interactions = $-.21$ ($p = .004$). Family caregivers rated the importance of care values to the PWD as lower than the PWD rated the importance. Determinants of greater incongruence included higher relationship strain and fewer positive dyadic interactions.

Conclusion—Our findings reveal significant levels of incongruence in perceptions of the PWD's values among dementia care dyads in the hospital setting. Our analysis suggests a potential impact of relationship variables on incongruence. Further research is needed around this overlooked interpersonal context for supporting the dementia care dyad in the hospital setting.

Keywords

incongruence; interpersonal context; dyadic; family caregiving; hospitalization

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Inpatient hospitalizations occur at least twice as often for persons with dementia (PWDs) compared with other older adults in the United States (Phelan, Borson, Grothaus, Balch, & Larson, 2012; Thies & Bleiler, 2013). During a hospitalization, clinical situations arise (e.g. decline in functional abilities) that can change the course of the PWD's post-hospitalization care. Care planning is important for families with dementia throughout the illness trajectory, but a hospitalization is an especially crucial time for families to come together and discuss the PWD's care values in light of the rapidly changing reality of their care needs (Bloomer, Digby, Tan, Crawford, & Williams, 2014).

It is the responsibility of hospitals under Medicare regulations to provide discharge-planning services (42 CFR § 482.43). Patients with cognitive impairment or dementia may not be able to make independent decisions about their discharge plan, which adds a layer of ethical complexity to achieving a safe and satisfactory discharge (Swidler, Seastrum, & Shelton, 2007). For example, the recommended level of post-hospital care in the discharge plan may be skilled nursing services in the home or in a facility. Most patients would be highly involved in choosing the option that best reflects their care values (i.e. the amount of importance assigned to aspects of care such as the quality of care or patient autonomy). The lack of time and inflexible routines in the hospital setting, however, create substantial barriers to the inclusion of both the PWD and family caregiver in conversations about the PWD's post-hospital care needs (Nilsson, Rasmussen, & Edvardsson, 2013). As a result PWDs can be excluded entirely from the hospital discharge planning process (Greener et al., 2012; Poole et al., 2014). Instead, family caregivers are often called upon to represent the PWD's care values (e.g. to organize one's own daily routine; to choose a specific individual to help with care) (Whitlatch, Piiparinen, & Feinberg, 2009), and approve the PWD's discharge plan in their place (Emmett, Poole, Bond, & Hughes, 2013).

Although PWDs can give consistent and reliable information about their care values (Feinberg & Whitlatch, 2001; Whitlatch, Feinberg, & Tucke, 2005), post-hospital care planning requires additional cognitive abilities including executive function and insight (Sorensen, Mak, & Pinguart, 2011), which decline in dementia (Kensinger, 2009). Family caregivers provide most of the care for PWDs in the community (Thies & Bleiler, 2013), and are looked to by providers in the outpatient and inpatient hospital settings to make surrogate decisions for the PWD, even when PWDs want to participate in their own care planning (Emmett et al., 2013; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Karlawish, Casarett, Propert, James, & Clark, 2002). The term *surrogate* assumes that the decision-makers are representing the PWD's values (Koppelman, 2002), and that they are using the substituted judgment standard (a decision the patient would have made if able) (Shalowitz, Garrett-Mayer, & Wendler, 2006). Without adequate knowledge of PWDs' care values, family caregivers are less likely to use the substituted judgment standard (Hirschman, Kapo, & Karlawish, 2006), and PWDs are more likely to receive unwanted care, such as hospitalizations at the end-of-life (Caplan, Meller, Squires, Chan, & Willett, 2006). Thus, it is important for family caregivers to know the PWD's care values, especially given the substantial pressure to make important decisions prior to the PWD's hospital discharge (Greener et al., 2012).

Incongruence in Perceptions of the PWD's Care Values

Studies in the community setting have demonstrated that incongruence regarding care values and preferences of PWDs is common in dementia care dyads (Carpenter, Kissel, & Lee, 2007; Heid, Bangerter, Abbott, & Van Haitsma, 2015; Reamy, Kim, Zarit, & Whitlatch, 2011). Typically, family caregivers have been found to underestimate the importance that PWDs assign to their values and preferences around everyday care (Heid et al., 2015; Moon, Townsend, Whitlatch, & Dilworth-Anderson, 2016; Reamy et al., 2011). This underestimation is also consistent with studies of incongruence regarding a variety of concepts (e.g. social and emotional functioning, quality of life, and interest in medical decision making) in PWD-family caregiver dyads (Hirschman et al., 2005; Moyle, Murfield, Griffiths, & Venturato, 2012; Nelis et al., 2011). Lower levels of incongruence surrounding everyday care values (e.g. keeping safe) and end-of-life care preferences have been found among African American dyads (Reamy et al., 2011; Schmid, Allen, Haley, & Decoster, 2010) and in dyads with patients who are more cognitively impaired (Buckley et al., 2012; Reamy et al., 2011). Some factors that are more amenable to intervention have also emerged, such as more family caregiver strain from providing care, and greater perceptions of relationship strain (Lyons, Zarit, Sayer, & Whitlatch, 2002; Sands, Ferreira, Stewart, Brod, & Yaffe, 2004). We lack knowledge, however, of the extent and outcomes of PWD-family caregiver incongruence in the acute care setting, where the need to make a care plan for PWDs is much more pressing and impactful.

Conceptual Model: The Stress Process Model

The Stress Process Model (SPM) addresses the process through which stress arises and is sustained when caring for a family member with an illness such as dementia (Pearlin, Mullan, Semple, & Skaff, 1990). The original SPM by Pearlin et al. (1990) was conceived with the family caregiver's stress process in mind, even though aspects of the dementia illness experience (e.g. cognitive impairment) are included in the model since they are sources of stress for the caregiver. The SPM has since been adapted into a version for the PWD's stress process (Judge, Menne, & Whitlatch, 2010). In order to inform a dyadic perspective of care planning for dementia, we drew upon both the PWD and family caregiver versions of the SPM for the current study.

SPM Outcome

According to Pearlin et al. (1990), the outcomes of the stress process are multiple, layered, and interrelated. There is an emphasis on outcomes of wellbeing, such as depressive symptoms, physical health, and quality of life. By combining the two versions of the SPM, we sought to encompass both the PWD's and the family caregiver's wellbeing as outcomes (Judge et al., 2010; Pearlin et al., 1990). Since quality of life may be negatively impacted by incongruence in PWD-family caregiver dyads (Moon et al., 2016), in this study we operationalized the outcome of the stress process as incongruence regarding the PWD's care values (see Figure 1).

Primary Stressors

The stressors encountered as a direct result of the experience of living with dementia or caring for a family member with dementia are labeled as primary stressors in the SPM. A fundamental primary stressor from both versions of the SPM is the PWD's cognitive function (Judge et al., 2010; Pearlin et al., 1990). Additionally, for family caregivers, the strain (or role overload/burden) that arises directly from caring for a family member with dementia is of primary importance to the stress process (Menne, Judge, & Whitlatch, 2009; Pearlin et al., 1990). Both cognitive impairment (Buckley et al., 2012; Reamy et al., 2011) and care-related strain (Sands et al., 2004) have also been found to be determinants of PWD-family caregiver incongruence in the broader literature.

Secondary Strains

In the SPM, secondary strains are additional sources of stress that occur as a result of primary stressors. The relationship between two family members necessarily changes as a result of living with dementia and taking on the roles of caregiver and care receiver. As Pearlin et al. note regarding the dementia care dyad: 'the involuntary transformation of a cherished relationship is a major source of stress' (1990, pg. 584). Indeed, relationship strain within the care dyad is associated with incongruence (Lyons et al., 2002), and poorer relationship quality diminishes the family caregiver's wellbeing (Pinquart & Sorensen, 2006). Additionally, effective interpersonal processes between the PWD and family caregiver are essential to achieving person-centered dementia care (Vernooij-Dassen & Moniz-Cook, 2016).

Two aspects of the care dyad's relationship were included as secondary strains in this study—negative dyadic strain and positive dyadic interactions—which Sebern & Whitlatch (2007) determined to be independent constructs of the Dyadic Relationship Scale (see Figure 1). Negative dyadic strain and positive dyadic interactions have previously been conceptualized and applied as secondary strains of the SPM (Judge et al., 2010; Menne & Whitlatch, 2007). Whereas negative dyadic strain represents appraisals of the difficulty of being in a family care relationship, positive dyadic interactions represent appraisals of the improved closeness and other gains associated with the care situation. Rather than representing opposing ends of the same continuum, these two appraisals can exist simultaneously (e.g. high dyadic strain in combination with high positive dyadic interactions) (Sebern & Whitlatch, 2007).

It is the goal of this study to learn more about incongruence within the inpatient hospital setting. Understanding incongruence in perceptions of the PWD's care values, and which dyads are at greater risk of incongruence in the hospital setting, would enable providers to recognize and prioritize dyads who may need additional support in care planning at this crucial time. Thus, the objectives of this study were:

1. Describe PWD-family caregiver incongruence in perceptions of the care values of hospitalized PWDs.
2. Identify determinants of incongruent perceptions of the care values of hospitalized PWDs.

Method

Participants and Procedures

Recruitment took place in adult inpatient acute care units in a university hospital in the Pacific Northwest. Approval was obtained from the Institutional Review Board for this study. Convenience sampling was used to enroll 42 dyads that met the following eligibility criteria. **Inclusion criteria.** PWDs were eligible if they were admitted to an acute care unit, age 65 or older, exhibited 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. Additionally, PWDs needed to score at least 13 on the Mini-Mental State Exam (moderate dementia), 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 et al., 2005). Family caregivers were eligible if they were designated 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), and age 21 or older. **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 the researcher approaching the dyad.

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. If PWD and family caregiver were interested, the researcher met with each member of the dyad to describe the study, assess eligibility, and obtain informed consent. Individual members of each dyad completed one private interview in-person within the acute care unit (without the other member of the dyad present). Participants were provided with written cards to aid memory about response scales and answered verbally to questions from the researcher. Responses were recorded electronically by the researcher on a laptop using REDCap, an electronic data capture and storage system.

Outcome Measure

Care Values of PWDs were measured among PWDs and family caregivers using equivalent versions of the Care Values Scale developed specifically for care dyads where the care recipient is a person with cognitive impairment (Whitlatch et al., 2009). The measure consists of four subscales: the 7-item autonomy subscale (reliability in this study: Cronbach's $\alpha = .51$ for PWD, $\alpha = .79$ for family caregiver. Example item: "how important is it for you/your family member to come and go as you please?"); the 5-item burden subscale (reliability in this study: Cronbach's $\alpha = .57$ for PWD, $\alpha = .77$ for family caregiver. Example item: "how important is it for you/your family member to avoid being a physical burden?"); the 7-item safety/quality of care subscale (reliability in this study: Cronbach's $\alpha = .62$ for PWD, $\alpha = .61$ for family caregiver. Example item: "how important is it for you/your family member to be safe from crime?"); and the 5-item social interactions subscale (reliability in this study: Cronbach's $\alpha = .50$ for PWD, $\alpha = .60$ for family caregiver.

Example item: “how important is it for you/your family member to be a part of family celebrations?”). Each item was rated by the PWD and family caregiver according to the importance to the PWD on a 3-point scale: 1= not at all, 2= somewhat, 3= very. Means for each subscale are used as summary scores, with higher scores indicating more importance of the care value to the PWD. This measure has previously been used among older adults with cognitive impairment and their family caregivers, with established validity (divergent, convergent, and content), and reliability (Whitlatch et al., 2009).

Primary Stressors

Cognitive status was screened and measured in PWDs with the 11-item Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). The MMSE is designed for clinician assessment of orientation, working memory, language, delayed recall, and attention/comprehension. The scale range is 0 to 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 PWD. Caregivers respond to three 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). For example, one of the items is: “you have more things than you can handle.” The items were summed for a scale range of 3 to 12. Higher scores indicate high levels of care-related strain. The reliability in this sample was adequate ($\alpha = .75$).

Secondary Strains

Dyadic strain and positive dyadic interactions were measured in family caregivers using the 5-item Dyadic Strain subscale and the 6-item Positive Dyadic Interactions subscale of the Dyadic Relationship Scale (Sebern & Whitlatch, 2007). We included the family caregivers’ report rather than the PWDs’ report due to missing PWD data and previous literature indicating the family caregivers’ perceptions of relationship strain were significantly associated with incongruence whereas the care recipient’s perceptions were not (Lyons et al., 2002). Each item on the Dyadic Relationship Scale is a statement of a potential source of strain or positive interaction in the relationship, for which family caregivers rated their level of agreement from 1 (strongly disagree) to 4 (strongly agree). Example items are: “Because of helping my family member, our relationship is strained” (dyadic strain subscale); “Because of helping my family member, communication between us has improved” (positive dyadic interactions subscale). Items are averaged for a scale range of 1 to 4, with higher scores indicating more perceived strain in the relationship/more perceived positive interactions in the relationship. In this sample, the reliability was acceptable for both subscales (dyadic strain $\alpha = .85$; positive dyadic interactions $\alpha = .79$), and the Pearson’s correlation between subscales was insignificant ($r = .01$; $p = .94$).

Analytic Approach Aim 1

The analysis of incongruence was performed using multilevel modeling and the software program HLM, version 7 (Raudenbush, Bryk, & Congdon, 2011). An approach such as multilevel modeling, where patients and family members are nested as individuals within a dyad, is optimal since it accounts for the non-independence of dyadic data. Previous studies have used multilevel modeling to examine incongruence within care dyads that included frail older adults with mild cognitive impairment and PWDs (Lyons et al., 2002; Reamy et al., 2011) and other family care dyads (Cano, Johansen, & Franz, 2005; Miller, Lyons, & Bennett, 2015; Winters-Stone, Lyons, Bennett, & Beer, 2014). Multilevel modeling is preferable to other methods of analyzing dyadic incongruence (e.g. difference scores, intraclass correlations, ANOVA) because it estimates latent scores for examining the direction of incongruence both within dyads and between dyads and accounts for non-independence of dyadic data by estimating and controlling for the degree of shared variance (Sayer & Klute, 2005).

Using the univariate model in HLM, a regression line with an intercept and a slope was calculated for each dyad's score on each care values subscale, as indicated in the following equation:

$$[Y_{ij} = \beta_{0j} + \beta_{1j}(\text{Dyad}_{ij}) + r_{ij}]$$

Level 1 data included individual observations of PWDs' and family caregivers' perceptions of care values, which were nested within the level 2 PWD-family caregiver dyad (the unit of analysis). The level 1 model estimated fixed effects, including the average values for the intercept (β_{0j}), which is the population's average care values score for the dyad, and the slope (β_{1j}), which represents the magnitude and direction of incongruence in perceptions of care values. By coding PWDs' scores as $-.5$ and family caregivers' scores as $.5$ in Dyad_{ij} , the direction of incongruence can be interpreted from the slope (β_{1j}). Thus, if family caregivers on average underestimate the importance of PWDs' values, the resulting β_1 coefficient will be negative.

Level 1 analysis also estimated random effects, including the variability around the intercept and slope. If there is significant variability around the average slope, predictors of the variability can then be examined in the Level 2 model (see Aim 2). The ability to examine this variability and go beyond group differences is a distinct advantage of multilevel modeling.

Analytic Approach Aim 2

Based on the SPM and previous incongruence literature, independent variables (cognitive impairment, care-related strain, dyadic strain, and positive dyadic interactions) were included in the MLM level 2 models, where the slope becomes the outcome variable of incongruence. Determinants of PWD-family caregiver incongruence were analyzed at level 2 by simultaneously including all independent variables into equations (resembling multiple regressions) that modeled the average incongruence (slope; β_{1j}) for each care values

subscale. The resulting coefficients can be interpreted as unstandardized regression coefficients similar to those found in simultaneous regression analysis.

Results

Persons with dementia were on average 80 ± 8 years of age, predominantly non-Hispanic white ethnicity/race (95%), had an average MMSE score of 21 ± 4 , and a slight majority (55%) were male. 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. There were no significant correlations between any of the independent variables (results not shown). See Table 1 for additional demographic and descriptive data.

Aim 1 results

On average dyads rated the importance of the care values to the PWD as follows (scale of 1 = not important, to 3 = very important): autonomy 2.36 ($p < .001$); avoiding being a burden 2.37 ($p < .001$); safety/quality of care 2.50 ($p < .001$); and social interactions as 2.29 ($p < .001$). There was a significant amount of incongruence, on average, for all 4 care values subscales (see Table 2): autonomy = -0.33 ($p < .001$); avoiding being a burden = $-.49$ ($p < .001$); safety/quality of care = $-.26$ ($p < .001$); social interactions = $-.21$ ($p < .01$). For all care values, the direction of incongruence was such that the family member rated the importance of care values to the PWD as lower than the PWD rated them. There was a significant amount of variability around the average amount of incongruence for the values of autonomy ($\chi^2 = 73.26$, $p < .001$), burden ($\chi^2 = 109.43$, $p < .001$), and safety/quality of care ($\chi^2 = 64.39$, $p = .007$), but not for the value of social interactions ($\chi^2 = 44.34$, $p = .256$).

Aim 2 results

In the level 2 model, independent variables were simultaneously introduced to explain the variability around the average incongruence in perceptions of the PWD's care values (see Table 3). Determinants of incongruence included fewer positive interactions for the value of autonomy, and greater relationship strain for the value of safety/quality of care, controlling for the primary stressors. Neither of the primary stressors (cognitive impairment or care-related strain) were significant determinants of any of the incongruence models, controlling for the secondary strains.

Discussion

Many difficult decisions are made about the PWD's care while in the inpatient hospital setting, and incongruence in perceptions of the PWD's care values limits the family caregiver's ability to make decisions in accordance with those values. This was the first known study to examine incongruent perceptions of PWDs' care values in the inpatient hospital setting. We found that: 1) on average, there was a significant amount of incongruence in perceptions across all four of the PWD's care values, with family caregivers rating the importance for each care value lower than the PWD; 2) there was significant

variability around the average amount of incongruence for all care values except the value of social interactions; 3) factors associated with incongruence included the secondary strains related to the dyad's relationship.

The family caregiver's knowledge of the PWD's care values can help inform difficult discharge decisions, such as whether it is more important to the PWD to emphasize safety over autonomy. Consistent with previous studies conducted in the community setting, family caregivers rated all four care values as being less important to the PWD than the PWDs themselves rated the importance of their care values (Moon et al., 2016; Reamy et al., 2011). The results of this study appear to confirm the "systemic discrepancies" noted by Reamy et al. (2011, pg. 479) in dyads' perceptions of the PWD's care values, and adds evidence for the direction of incongruence as underestimation by family caregivers. It is perhaps unsurprising that, in the midst of a hospitalization, dementia care dyads would also exhibit the incongruent perceptions regarding care values that they held in the community setting. Yet, it was necessary to confirm and learn more about incongruence in the hospital setting, where there is so much at stake around the post-hospital care decisions.

It is important to note that while there was significant incongruence, on average, for all care values, there was no significant variability around the average amount of incongruence regarding the value of social interactions. Thus, the average incongruence regarding the value of social interactions was representative of dyads in this sample and we were unable to examine potential predictors of variability (Aim 2). However, there was significant variability around the average amount of incongruence for the values of autonomy, burden, and safety/quality of care, which indicates that the average was not representative of all dyads in this sample, and opens up the possibility for future studies to examine types of dyads that fit different patterns of incongruence (i.e. varying magnitudes and directions).

The second objective of this study was to identify determinants of incongruence in perceptions of the PWD's care values using the SPM as a conceptual framework. The secondary strains (dyadic strain and positive dyadic interactions) were significant determinants of PWD-family caregiver incongruence regarding two of the PWD's care values. The family member's appraisal of greater strain in the dementia care dyad's relationship was a significant determinant of incongruence regarding perceptions of the PWD's value of safety/quality of care. Safety/quality of care is arguably the most easily communicated of the four care values. Thus, the influence of dyadic strain on this particular value could be reflecting a more fundamental deterioration in the care dyad's relationship, whereby family caregivers who are resentful and angry, for example, may not recognize or appreciate the PWDs' signals about the importance of safety and quality of care in their lives.

Meanwhile, fewer positive dyadic interactions were a significant determinant of incongruence regarding perceptions of the PWD's value of autonomy. According to Sebern & Whitlatch (2007), positive dyadic interactions are not necessarily in conflict with dyadic strain, and indeed there was no correlation between the two subscales in this study. Positive dyadic interactions represent the gains experienced by entering into a care relationship (e.g. closeness, communication, learning good things about each other). For family caregivers, a

lack of positive dyadic interactions may signify a process of distancing themselves from PWDs, thereby learning less about what is important to them, such as the value of autonomy. The process of “role disengagement” has previously been described as one of the stages of the family caregiver’s relationship with the PWD (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Thus, one possible explanation for this finding is that the family caregiver needs to experience a certain degree of closeness and open communication with the PWD in order to recognize the importance of autonomy. Overall, the role of these relationship variables in explaining incongruence implies that interventions could potentially improve the family caregiver’s knowledge of the PWD’s care values by offering ways engage in positive dyadic interactions, and mitigate strain in the relationship.

The primary stressors—cognitive impairment and care-related strain—were not significant determinants of incongruence in this study, which is contrary to some, but not all, of the previous incongruence research. In PWD-family caregiver dyads, higher levels of cognitive impairment were associated with lower levels of PWD-family caregiver incongruence in two studies (Buckley et al., 2012; Reamy et al., 2011), but no association was found in a third study (Sands et al., 2004). Care-related strain is an individual construct reflecting the degree to which a family member feels overwhelmed in the role of caregiver. It is possible that since PWDs in this study were being cared for in the hospital, some family caregivers may have felt some temporary relief in their caregiving role. However, on average, the amount of care-related strain reported in this sample was still substantial (see Table 1). Alternatively, the phenomenon of experiencing both caregiving gains and strains has been well documented (Schulz & Sherwood, 2008), and may in part explain this finding since family caregivers reported high levels of positive interactions, which were clearly more influential on incongruence in this study.

This study was not without limitations. Firstly, the measure used for the care values of PWDs, while psychometrically sound in its development (Whitlatch et al., 2009), resulted in low reliability on several subscales in this study, especially for PWDs. We believe that the low alphas on the care values subscales may be due to a combination of the small sample size and the small number of items per subscale. It is possible that the lower than desired reliability may have attenuated the potential associations examined in this study. Secondly, our modest sample of 42 dyads constrained the selection of variables and the generalizability of findings, which was also quite limited by the homogeneity of the participants’ ethnicity and race (over 90% non-Hispanic white). We were unable to evaluate race as a covariate in this study, however, previous research has revealed greater congruence among African American dyads compared with Caucasian dyads in both non-cognitively impaired and in cognitively impaired patients (Reamy et al., 2011; Schmid et al., 2010). Culture and family context are likely to influence dyads’ conversations about and understanding of the PWD’s care values. Thus, replication with a larger, more diverse sample is an important next step to overcome these limitations and confirm our findings. Finally, despite the testing of our framework, the cross-sectional design limited our ability to establish the temporal precedence for secondary strains as determinants of incongruence in perceptions of the PWD’s care values. There are few longitudinal studies of incongruence, and it is an important direction for future research because examining incongruence in perceptions of

the PWD's values over time would enable us to better support dyads in the care planning process.

Despite these limitations, the study had several notable strengths. We expanded the study of incongruence in dementia care dyads to a new setting—the inpatient hospital setting—which is a crucial moment in the care planning for PWDs. We applied theoretical work on the stress process of family caregivers and PWDs as a guide for this dyadic study of care values. Lastly, we learned more about the effect of the interpersonal context of incongruence by including both negative and positive aspects of the relationship in our models examining the determinants of incongruence.

In order to empower family caregivers to make decisions for PWDs that are in line with PWDs' care values, it is first necessary to identify dyads most at risk for incongruence, particularly in the inpatient hospital setting where important decisions about the PWD's care may occur at a rapid pace. The current study was a beginning step toward understanding which dyads may be at increased risk of incongruence in the hospital setting, namely those with more dyadic strain and fewer positive dyadic interactions. The role of the interpersonal context should be confirmed in future research with larger, more diverse samples of dementia care dyads. Despite the challenges of a hospitalization and the stress process of living with dementia, there is still the potential for the dyad's relationship to play a role in minimizing incongruence.

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Figure 1. Conceptual model for this study, adapted from versions of the Stress Process Model for family caregivers (Pearlin et al., 1990), and for PWDs (Judge et al., 2010).

Table 1

Sample demographics (N=42 Dyads) and measure descriptives

	PWD Mean (SD) or %	CG Mean (SD) or %
Age in years *	79.81 (7.76)	61 (12.95)
Female	45.24%	75%
Education (> high school diploma)	69%	84.6%
Race/Ethnicity		
White (Non-Hispanic)	95.24%	92.5%
Black/African-American	2.38%	2.5%
Native American/Pacific Islander	0%	0%
Asian	2.38%	5%
Hispanic/Latino	2.38%	2.5%
Marital Status (married/partnered)	40.0%	62.5%
Relationship to Patient		
Wife	-	22.5%
Husband	-	7.5%
Adult Daughter	-	50.0%
Adult Son	-	17.5%
Daughter-in-law	-	2.5%
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, scale 0–30)	20.55 (3.86)	-
Care-Related Strain (Role Overload, scale 3–12)	-	7.9 (2.62)
Dyadic Strain (scale 1–4)	-	2.02 (.72)

* Ages 90 years or older were all recorded as 90+ to protect identity.

PWD = person with dementia. CG = family caregiver. MMSE = Mini-mental state examination

Table 2
Level 1 Models, Perceptions of the PWD's Care Values: Dyadic Means and Incongruence Scores

	Autonomy			Burden			Safety/Quality of Care			Social Interactions		
	β	SE	df	β	SE	df	β	SE	df	β	SE	df
Fixed effects												
Intercept	2.36***	.05	41	2.37***	.05	41	2.50***	.05	41	2.29***	.05	41
Slope	-.33***	.07	41	-.49***	.09	41	-.26***	.06	41	-.21**	.07	41
	Autonomy			Burden			Safety/Quality of Care			Social Interactions		
Random effects	variance	χ^2	df	variance	χ^2	df	variance	χ^2	df	variance	χ^2	df
Intercept	.09	175.15***	39	.08	136.30***	39	.06	137.89***	39	.08	112.99***	39
Slope	.09	73.26***	39	.23	109.43***	39	.06	64.39**	39	.03	44.34	39

***
 $p < .001$;

**
 $p < .01$;

PWD= person with dementia.

Table 3
Level 2 Models, Determinants of Incongruence in Perceptions of the PWD's Care Values

	Autonomy				Burden				Safety/Quality of Care			
	β	SE	df		β	SE	df		β	SE	df	
Fixed effects												
Slope (incongruence)	-.33***	.07	34		-.49***	.09	34		-.26***	.06	34	
Cognitive Function	.02	.02	34		.04	.03	34		.00	.03	34	
Care-Related Strain	-.01	.03	34		.02	.04	34		-.01	.03	34	
Dyadic Strain	.11	.09	34		-.15	.14	34		-.15*	.07	34	
Positive Interactions	.24*	.10	34		-.07	.20	34		-.17	.11	34	
	Autonomy				Burden				Safety/Quality of Care			
Random effects	variance component	χ^2	df		variance component	χ^2	df		variance component	χ^2	df	
Slope (incongruence)	.07	64.53***	34		.21	102.24***	34		.05	56.51***	34	

***
 $p < .001$;

**
 $p < .01$;

*
 $p < .05$;

PWD= person with dementia.