Planning for Dementia Care Together: A Study of Hospitalized Patient-Family Caregiver Dyads

By

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Abstract

Background: Diagnosis of dementia in the early stage is becoming common and can give families the time they need together to adjust and plan for the future. However, early diagnosis does not always result in early care planning. The purpose of this manuscript dissertation was to examine two aspects of dementia care planning–the decision-making involvement and care values of the person with dementia (PWD)–particularly within the context of an acute care hospitalization and from the perspectives of the PWD and family caregiver.

Methods: First, a systematic literature review was performed in order to identify the extent and known determinants of greater involvement of PWDs in the decision-making process. Next, a study was conducted in the inpatient hospital setting with 42 dyads comprised of a PWD and a family caregiver. Finally, the dyadic data was analyzed using multilevel modeling in order to address two aims related to aspects of care planning: 1) to examine the involvement of PWDs in everyday decision making from the perspectives of PWDs and their family caregivers, and to identify factors thereof; 2) to describe and identify determinants of incongruent perceptions of the care values of PWDs.

Results: According to the literature review the lack of involvement of PWDs in decision making is influenced by a number of factors, only a few of which are modifiable. In the empirical results from **Aim 1**, both PWDs and family caregivers were significantly more likely to perceive greater PWD involvement in decision making when the family caregiver reported the PWD as valuing autonomy. PWDs were significantly more likely to report greater involvement when they had greater cognitive function. Family caregivers perceived significantly greater involvement of the patient in decision making when they reported less strain in the relationship. **In Aim 2**, 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. Factors associated with incongruence included relationship strain and fewer positive interactions in the dyad.

Conclusions: This dissertation offers a beginning step toward improving the care planning process for PWDs and their family caregivers in the inpatient hospital setting and beyond. The extent of cognitive impairment is limiting factor for PWDs' involvement. Yet, finding ways for the family caregiver to recognize the importance of autonomy to the PWD, and supporting the care relationship between the PWD and family caregiver, will be promising targets for future research aimed at understanding and intervening in the care planning process of dementia care dyads.

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CHAPTER I – Introduction to the Dissertation

Irreversible progressive dementias are terminal neurodegenerative syndromes that affect the intellectual and physical function of over 35.6 million older adults worldwide (Prince et al., 2013). The underlying pathology of dementia (as the group of neurodegenerative syndromes will be referred to in this dissertation) most commonly involves one or more of the following: Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, or frontotemporal lobar degeneration (Alzheimer's Association, 2014). Dementia is a phenomenon of aging: the prevalence increases from 5-7% of adults age 60 and older to more than 33% of adults age 85 and older (Alzheimer's Association, 2014; Prince et al., 2013). Although there are a lack of clinically effective treatments for slowing or halting the disease, recent advances in imaging and biomarkers have improved clinicians’ ability to make an early diagnosis (Johnson et al., 2013; Perrin et al., 2011; Rowe et al., 2013). Early diagnosis provides persons with dementia (PWDs) and their families a longer window for planning together for future dementia care (Borson et al., 2013). However, little is known about how best to support PWDs and family caregivers during care planning, or how to recognize PWD-family caregiver dyads that may need additional assistance in planning for future care.

Increasingly, researchers recognize that PWDs should be included in decisions about their care (Bartlett & O'Connor, 2007; Feinberg & Whitlatch, 2002; Horton-Deutsch, Twigg, & Evans, 2007; McCormack, 2002; Menne & Whitlatch, 2007; Murphy & Oliver, 2013). One notable influence on the movement to include PWDs is the philosophical view of personhood (Kitwood & Bredin, 1992), and its clinical manifestation, person-centered care. Person-centered care is often promoted as the standard by which quality dementia care is measured (Brooker, 2007; Edvardsson, Sandman, & Borell, 2014; Edvardsson, Winblad, & Sandman, 2008), and has influenced the health care policies of countries such as England, Norway, Sweden, and Australia (Boyle, 2008; Edvardsson et al., 2014; Fortinsky & Downs, 2014; Jowsey, Yen, Wells, & Leeder, 2011). Person-centered dementia care has been defined as: “supporting the rights, values, and beliefs of the individual; involving them and providing unconditional positive regard; entering their world and assuming that there is meaning in all behavior, even if it is difficult to interpret; maximizing each person’s potential; and sharing decision making” (Edvardsson et al., 2008). Although person-centered care has generally been positively conceptualized, especially among nurse researchers (Buron, 2008; Chenoweth et al., 2009; Edvardsson, Nilsson, Fetherstonhaugh, Nay, & Crowe, 2013; Ericson, Hellström, Lundh, & Nolan, 2001; McCormack & McCance, 2006; Penrod et al., 2007; Specht, Taylor, & Bossen, 2009; Stein-Parbury et al., 2012), adopting it for the purposes of care planning presents major challenges.

One of the biggest challenges to including PWDs in their own care planning is finding the balance with the involvement of family members (Tyrrell, Genin, & Myslinski, 2006). Patients have the right to self-determination in healthcare as long as they have decisional capacity (Beauchamp & Childress, 2009; Karlawish, 2008). When decisional capacity diminishes, which can be early in the disease process, family caregivers begin to take over for PWDs in care planning (Hirschman, Joyce, James, Xie, Casarett, et al., 2005; Karlawish, 2008). Yet, even if a patient lacks capacity or capacity is in question, there is nothing precluding the patient from participating in care planning along with their family members (Fetherstonhaugh, Tarzia, & Nay, 2013). Furthermore, inclusion of the PWD in decision making, whether or not they make the final decision, may improve the family caregiver’s wellbeing (Menne, Tucke, Whitlatch, & Feinberg, 2008).

There are particular challenges to supporting the PWD-family caregiver dyad in the acute care setting, where efficiency and specialization drive care (Nilsson, Rasmussen, & Edvardsson, 2013). In the interest of efficiency, health care providers often bypass the PWD, and instead look to family caregivers to take charge of care planning and make surrogate decisions for PWDs (Kapp, 2002; Nilsson et al., 2013). According to law and ethics, surrogate decision makers should be using the substituted judgment standard, which is making the choice that reflects the patient's values. This method preserves patient autonomy to some degree (Hirschman, Kapo, & Karlawish, 2006; Tsou & Karlawish, 2014). Yet, we know that family caregivers are not very accurate as surrogate decision-makers (Shalowitz, Garrett-Mayer, & Wendler, 2006), and they are challenged by the substantial pressure and time constraints of the acute care setting (Nilsson et al., 2013). Thus, it is important to learn more about how to increase family caregivers' knowledge of the PWD's care values, especially in the inpatient hospital setting where many decisions are made.

The intersection of the issues of surrogate decision-making, decision-making involvement, and self-determination can be conceptualized as a hierarchy of patient autonomy (see Figure 1). This dissertation is focused on the middle-ground between self-determination and surrogate decisions that are not based upon the patient's wishes or values (i.e. best interests standard). This grey middle ground (see Figure 1) is where both dyad members are either involved or represented in care planning. It is also where the most gains can be made in improving autonomy among persons with dementia. It is clear from the body of research on decision-making capacity that complete autonomy, or self-determination, is not possible for PWDs as they become more cognitively impaired (e.g. Arias, 2013; Gurrera et al., 2007; Moye et al., 2006). However, joint decision making is possible to a certain degree for PWDs depending upon their ability to communicate their values and preferences. When joint decision making is not possible, family caregivers will be tasked with making surrogate decisions, and ideally these decisions will be based upon the patient's values (i.e. substituted judgement standard).

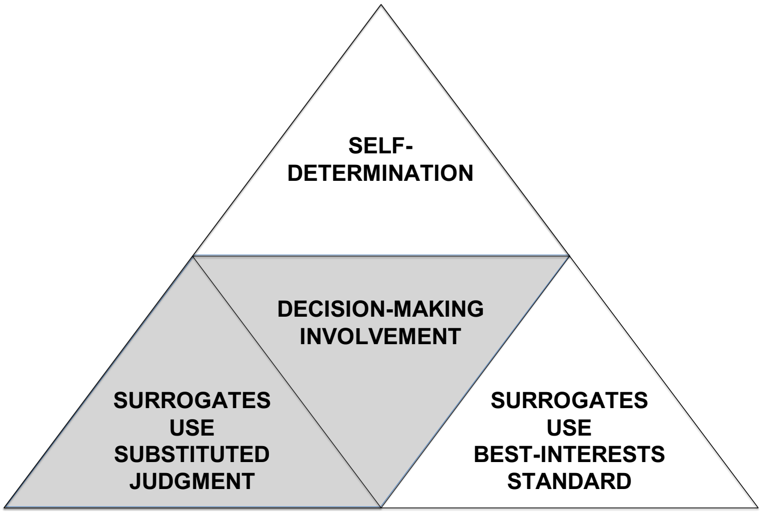

Figure 1. Hierarchy of Patient Autonomy *(focus of this dissertation shaded in grey)*

Dementia is a shared context for the PWD and family caregiver. It not only effects both individuals' lives, it changes the nature and quality of the relationship between them (Braun et al., 2009; Nelis et al., 2011). A dyadic approach to studying PWDs and their family caregivers allows researchers to gain a deeper understanding of the complexities of the relationship and the inter-relatedness of individual experiences (Lyons, Zarit, Sayer, & Whitlatch, 2002). Focusing on the dyad is also necessary in order to examine the interpersonal context of dementia care planning. The PWD-family caregiver dyad faces a number of stressors that are presumed to impact how they plan together as a unit (Menne & Whitlatch, 2007; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004). However, few studies have addressed the particular difficulties of supporting PWD-family caregiver dyads in their planning and decision-making within the acute care setting.

Theoretical Framework

The Stress Process Model (SPM) provided an explanatory framework for the interconnected stressors and strains that result from living with dementia (Judge, Menne, & Whitlatch, 2010; Pearlin, Mullan, Semple, & Skaff, 1990). The original SPM by Pearlin et al. (1990) was conceived with the family caregiver's stress process in mind. The SPM has since been adapted into a version for the PWD's stress process (Judge, Menne, et al., 2010). In the conceptualization of stressors and strains for this dissertation work, the two versions of the SPM were used and integrated to maintain a dyadic perspective of the illness experience (Judge, Menne, et al., 2010; Pearlin et al., 1990). The integrated version of the SPM is displayed in Figure 2.

In the SPM that was adapted for this dissertation, it is presumed that stressors and strains have an impact upon the two main outcomes of interest: the decision-making involvement of PWDs, and incongruence regarding the care values of PWDs. There are two major components of the SPM that could influence such outcomes (see Figure 2). 1) Primary stressors are encountered as a direct result of the experience of living with dementia or caring for a family member with dementia. Primary stressors can be objective (e.g. pathologies of the disease/cognitive impairment) and subjective (e.g. overload of care tasks or psychological distress of living with dementia). 2) Secondary strains are additional sources of stress that occur as a result of primary stressors. Secondary strains can be intrapsychic strains, described by Pearlin et al. (1990) as strains on "dimensions of self-concept" (e.g. importance of autonomy to the PWD), or role strains, such as strains on the dementia care dyad's relationship.

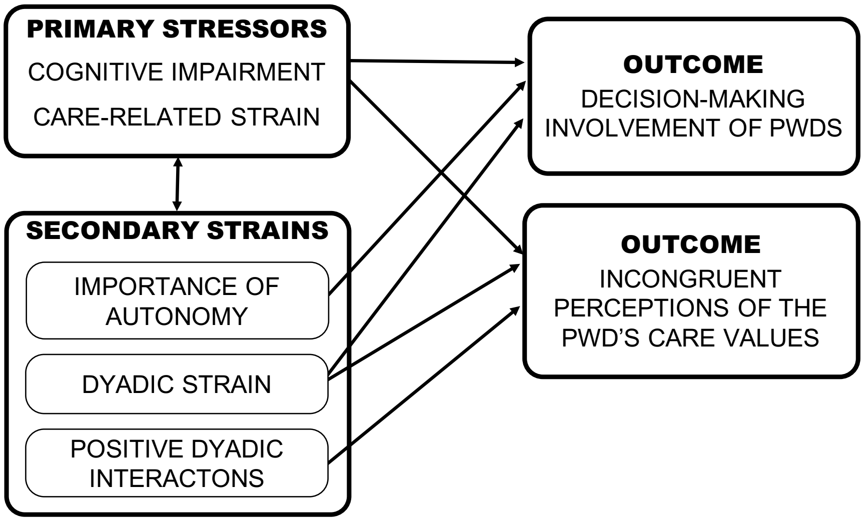

Figure 2. Unified Stress Process Model

Literature Review

This dissertation addressed two issues that are central to families who are planning for future dementia care: the PWD's decision-making involvement, and perceptions of the PWD's care values (which can be reflected in surrogate decisions). As described above and in Figure 1, self-determination, or autonomy, is the pinnacle of the hierarchy of patient autonomy in health care decisions (Beauchamp & Childress, 2009). Autonomy in the context of dementia has been the subject of theory and policy (Algase et al., 1996; Boyle, 2008; Kitwood & Bredin, 1992), with various calls for better inclusion of the PWD's perspective in research and clinical practice (Cotrell & Schulz, 1993; Downs, 1997; McCormack, 2002; Woods, 2001). However, it is also clear that dementia is a direct threat to PWDs' independent decision-making capacity.

Typically decision-making capacity is not formally assessed unless a potentially contentious issue such as driving cessation, living independently, or financial management is under consideration (O'Connor, Purves, & Downs, 2009). Decision-making capacity is a clinical judgement that applies to a specific decision, rather than unilaterally (Karlawish, 2008; Moye & Marson, 2007). One of the major difficulties in determining capacity is that incapacity in regard to one task or decision does not exclude capacity in regard to another task or decision (Sabat, 2005). Dementia per se does not prohibit independent decision-making, but impairments in reasoning and language that often occur in dementia affect decision-making capacity over time (Moye, Karel, Gurrera, & Azar, 2006). Incapacity in decision-making is often assumed of PWDs, even though formal assessments of decision-making capacity are not standard practice in healthcare settings (O'Connor et al., 2009). Thus, it is customary to rely upon family caregivers to make decisions for PWDs, regardless of whether legal or medical channels have established a PWD's incapacity (Kapp, 2002). These practices are being challenged with legislation such as the Mental Capacity Act 2005 (in England and Wales), which advances civil and social rights of PWDs, even when they have been determined to lack capacity, by promoting self-determination and facilitating autonomy in decision-making (Boyle, 2008; Samsi & Manthorpe, 2013).

There are several arguments to be made for involving both PWDs and family caregivers in the decision-making process. Persons with dementia maintain the ability to communicate values and preferences long after their decision-making abilities are affected by dementia (Whitlatch, Feinberg, & Tucke, 2005b). Research over the past 15 years has shown PWDs to be reliable self-reporters on a range of factors (e.g. quality of life, depressive symptoms, well-being, and care values and preferences), even through moderate stages of cognitive impairment (Feinberg & Whitlatch, 2001; Logsdon, Gibbons, McCurry, & Teri, 2002; Mak, 2011; Parmelee, Lawton, & Katz, 1989; Whitlatch et al., 2005b).

A lack of input from PWDs puts family caregivers in the difficult position of making decisions alone. Family caregivers who perceive less involvement from PWDs in decision-making have also reported lower quality of life, more depression, more negative strain, and are less congruent in their understanding of PWDs' values (Menne et al., 2008; Reamy, Kim, Zarit,

& Whitlatch, 2011). On the other hand, caregivers' involvement in decision-making for PWDs is often essential to the process of translating PWDs' values into decisions (Gillick, 2013). Due to cognitive changes that affect executive function and insight, PWDs often lack sufficient awareness of future care needs and become frustrated or confused by the process of decision-making (Kensinger, 2009; Orfei et al., 2010; Sörensen, Mak, & Pinquart, 2011). Additionally, family caregivers who are responsible for implementing the PWD's care need to assist in choosing the kind of care that they are realistically able to provide.

Decisions reflect values, since we arrive at a decision by actively supporting a value through choice (Koppelman, 2002). Ethical perspectives are divided over whether to adhere to the values or expressed wishes prior to dementia–known as precedent autonomy (Dworkin, 1993), or to represent the person's values as they evolve throughout dementia (Dresser, 2001; Dresser, 1992). The current culture of advance directives is in support of precedent autonomy, but there are also indications that these documents are not entirely useful to families of PWDs or to health care professionals (Robinson et al., 2013; Robinson et al., 2012). Firstly, not everyone completes an advanced directive. Family caregivers and PWDs have reported varied rates of engaging in advance care planning, falling within the range of 33-77% (Black et al., 2009; Hirschman, Kapo, & Karlawish, 2008; Hopp, 2000; Lingler et al., 2008; Pasman et al., 2004; Triplett et al., 2008). There is also much variability in the way these documents guide the decision-making process (Dening, Jones, & Sampson, 2013; Hirschman et al., 2006). In general, family caregivers who know PWDs' prior wishes do not always feel obliged to follow them (Elliott, Gessert, & Peden-McAlpine, 2007, 2009; Hirschman et al., 2006; Jox et al., 2012), and the existence of an advance directive does not decrease surrogate decision makers' uncertainty about their final decisions (Lopez & Guarino, 2011).

Understanding PWDs' current values may be a more important goal for both PWDs and family caregivers. Family caregivers identify the PWD's well-being more often than they identify advance directives as an important factor that influences their decision-making process (Jox et al., 2012; Kaldjian, Shinkunas, Bern-Klug, & Schultz, 2010; Kwok, Twinn, & Yan, 2007). According to Jaworska's philosophy of values in Alzheimer's disease, living in accordance with one's values is a major determinant of well-being (Jaworska, 1999). Values are intertwined with a person's sense of self, and we measure our self-worth according to how well we live up to our values (Jaworska, 1997, 1999). Additionally, there is nothing about expressing values that requires a grasp of one's whole life narrative (Jaworska, 1999). In other words, a person's memory does not need to be intact in order have values and communicate them to others. While espousing values does not require an intact memory, implementing values is an entirely separate task that is most certainly affected by dementia and often prohibits PWDs from making their own decisions. Jaworska addresses this dilemma by conceptualizing a modified "autonomy", whereby PWDs who are able to espouse values can be assisted in implementing them by other agents, such as family caregivers (Jaworska, 1999).

Typically, we rely upon family caregivers to communicate PWDs' values, but this is problematic given the evidence on the inaccuracy of proxy reporting and known discrepancies between PWDs and caregivers in their perceptions of PWDs values (Reamy et al., 2011; Shalowitz et al., 2006). For example, according to a systematic review, surrogate decision-makers are in general only accurate 68% of the time, and when the decision involves dementia care this estimate drops to 58% (Shalowitz et al., 2006). Also, relying upon family caregivers to communicate PWDs' values implicitly assumes that the family caregiver is a more important agent than the PWD, which reinforces PWD dependence. In turn, premature dependence deprives PWDs of personhood (Kitwood, 1990). Finally, family caregivers' perceptions of the importance of PWDs' values, on average, decrease over time (Reamy, Kim, Zarit, & Whitlatch, 2013), which is an indicator that family caregivers are influenced by factors other than their knowledge of PWDs' values.

Incongruence

Incongruence refers to differences between perceptions held by two people about the same construct, in this case values. Incongruence in perceptions of the PWD's values affects the family caregiver's ability to make surrogate decisions that reflect the PWD's values. Other studies have demonstrated PWD-family caregiver incongruence for a wide range of factors related to the PWD: quality of life (Buckley et al., 2012; Hoe, Katona, Orrell, & Livingston, 2007; Logsdon et al., 2002; Moyle, Murfield, Griffiths, & Venturato, 2012; Sands, Ferreira, Stewart, Brod, & Yaffe, 2004), social functioning (Nelis et al., 2011), depressive symptoms (Teri & Wagner, 1991; Weiner, Svetlik, & Risser, 1997), pain (Jensen-Dahm, Vogel, Waldorff, & Waldemar, 2012), involvement in making care decisions (Hirschman, Joyce, James, Xie, & Karlawish, 2005), and care values and preferences (Ayalon, Bachner, Dwolatzky, & Heinik, 2012; Carpenter, Kissel, & Lee, 2007; Reamy et al., 2011). Less PWD-CG incongruence has been found regarding the PWD's health status (Boyer, Novella, Morrone, Jolly, & Blanchard, 2004), physical function, and direct care needs (Lyons et al., 2002), which may be indicative of how observable the "object" of incongruence is in these studies (McPherson & Addington-Hall, 2003).

Family caregivers tend to underestimate the PWD's quality of life (Buckley et al., 2012; Conde-Sala, Garre-Olmo, Turro-Garriga, Lopez-Pousa, & Vilalta-Franch, 2009; Hoe et al., 2007; Logsdon et al., 2002; Moyle et al., 2012; Sands et al., 2004), the importance of care values and treatment preferences to the PWD (Carpenter et al., 2007; Heid, Bangerter, Abbott, & Van Haitsma, 2015; Moon, Townsend, Whitlatch, & Dilworth-Anderson, in press; Reamy et al., 2011), the PWD's awareness of socio-emotional functioning (Nelis et al., 2011), and the PWD's desire to be involved in decision-making (Hirschman, Joyce, James, Xie, & Karlawish, 2005; Menne et al., 2008). Conversely, family caregivers tend to overestimate the PWD's depressive symptoms (Teri & Wagner, 1991; Weiner et al., 1997) and pain (Jensen-Dahm et al., 2012). Researchers have attributed incongruence over aspects of PWD illness and disability to the family caregiver's appraisal related to the difficulty of the caregiving role (Long, Sudha, & Mutran, 1998; Lyons et al., 2002).

Significant PWD-family caregiver incongruence has been found in studies of the PWD's care values and preferences (Ayalon et al., 2012; Carpenter et al., 2007; Heid et al., 2015; Moon et al., in press; Reamy et al., 2011; Whitlatch, Piiparinen, & Feinberg, 2009). The most relevant study of PWD-family caregiver incongruence to this dissertation is one conducted by Reamy, Kim, Zarit, and Whitlatch (2011) surrounding the everyday care values of PWDs (e.g. to organize one's own daily routine; to choose a specific individual to help with care) (Reamy et al., 2011). Caregivers in this study systematically underestimated the importance to the PWD of all the care values that were measured (24 items covering 5 domains: autonomy, burden, control, family, and safety). Incongruence in perceptions of the PWD's care values limits the family caregiver's ability to make decisions in accordance with the PWD's care values–in essence, the ability to act as a surrogate. In order to empower family caregivers to make surrogate decisions for PWDs, it is first necessary to identify dyads most at risk for incongruence, particularly in settings where important decisions about the PWD's care may occur.

Despite the substantial amount of research indicating that PWD-family caregiver incongruence is common, less than half of studies have examined factors associated with PWD-family caregiver incongruence (Ayalon et al., 2012; Boyer et al., 2004; Buckley et al., 2012; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Lyons et al., 2002; Reamy et al., 2011; Sands et al., 2004), and the determinants of PWD-family caregiver incongruence are often constrained to background variables (age, gender, race, and cognitive impairment). Associations have been identified between lower levels of PWD-family caregiver incongruence and the family caregiver's race (African-American) and gender (female) (Hirschman, Joyce, James, Xie, & Karlawish, 2005; Reamy et al., 2011), and the PWD's gender (male) (Hirschman, Joyce, James, Xie, & Karlawish, 2005); although, for race the association was inconsistent in PWDs (Reamy et al., 2011). 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).

Although demographic and background variables, such as cognitive impairment, cannot be ruled out as contributing to PWD-family caregiver incongruence, they also cannot be modified. Some factors that are more amenable to intervention have emerged. A higher level of PWD-family caregiver incongruence is associated with depression in the PWD (Sands et al., 2004), less PWD decision-making involvement (Reamy et al., 2011), more family caregiver strain from providing care, and perceptions of relationship strain (Lyons et al., 2002; Sands et al., 2004). However, all of these factors were found to be significant when measured cross-sectionally in the community setting, and we lack knowledge of the extent and determinants of PWD-CG incongruence in the acute care setting, where the need to make a care plan for PWDs is much more pressing and impactful.

Purpose and Specific Aims

The purpose of this manuscript dissertation is to examine two aspects of dementia care planning within the context of an acute care hospitalization–the PWD's decision-making involvement and care values–from the perceptions of both members of the dementia care dyad. Few studies have examined PWD-family caregiver dyads in the acute care setting, and no previous study has examined perceptions of the PWD's care values or shared decision-making involvement in this setting. The body of the dissertation addresses this purpose in two specific aims (Table 1).

Table 1. Chapters and Aims

Chapter	Specific Aim
Chapter 2: Shared decision making in dementia: A review of patient and family carer involvement **Chapter 3**: Involvement of Hospitalized Persons with Dementia in Everyday Decisions: A Dyadic Study	**Aim 1:** To examine the decision-making involvement of persons with dementia
Chapter 4: Incongruent perceptions of the care values of hospitalized persons with dementia: A pilot study of patient-family caregiver dyads	**Aim 2:** To describe and identify determinants of incongruent perceptions of the care values of hospitalized persons with dementia

Summary

The goal of this body of work is to gain a greater understanding of the influence of the interpersonal context of the dementia care dyad on the PWD's involvement in care planning. Results from the empirical studies will contribute foundational information about the dyadic realities of the care planning process for PWDs and their family caregivers in the inpatient hospital setting. Nurses are poised to lead the way as the direct care staff who most frequently interact with patients and their families, and as the case managers who are primarily responsible for helping patients and families create the post-hospital discharge plan.

CHAPTER II

Shared decision making in dementia: A review of patient and family caregiver involvement

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This manuscript represents a significant contribution to the dissertation work, and replaces aspects of the traditional literature review chapter. This manuscript was accepted for publication on November 4th, 2014, in *Dementia*, an international indexed and peer-reviewed journal with a focus on social research and the lived experience of dementia. Permission to print the pre-publication version of this manuscript has been obtained from Sage Publications (See Appendix page 112-113).

Abstract

This paper reviews empirical findings concerning the decision-making process of persons with dementia and their family carers, with a particular focus on the extent and determinants of involvement of persons with dementia in the decision-making process. To be included in this review, studies needed to be published in peer-reviewed journals between 1999 and 2014, report empirical data from participants with dementia and/or their family carers, and pertain to the involvement of persons with dementia and their family carers in decisions about everyday care, medical care and treatment, or long-term care. A total of 36 studies were included. Results indicated that not all persons with dementia are excluded from participating in the decision-making process, but there is a broad spectrum of what constitutes shared decision-making in dementia. Studies concerning the determinants of shared decision-making mostly focused on non-modifiable factors. Future research is needed to better promote shared decision-making among persons with dementia and their family carers.

Keywords

Decision-making, caregiving, dementia, personhood, care values

Each of the 35.6 million families worldwide who are affected by dementia (Prince et al., 2013) must make decisions about everyday care, medical treatment, and long-term care arrangements. The decision-making process for persons with dementia and their family carers is fraught with complex family, ethical, and legal dilemmas. Many of these dilemmas hinge on the lack of involvement of the person with dementia in decisions about their own wellbeing and care. In the context of dementia, examinations of the decision-making process, as opposed to its outcomes, have often been limited in scope to one of two issues: determining the loss of decision-making capacity (e.g. Arias, 2013; Gurrera, Karel, Azar, & Moye, 2007; Moye et al., 2006), or establishing the family carer's responsibilities as a surrogate decision-maker (e.g. Jox et al., 2012; Smith, Lo, & Sudore, 2013). Questions surrounding the shared decision-making involvement of the person with dementia and family carer are relatively new explorations in dementia research, and offer possibilities for understanding the complexities of decision-making that extend beyond the dichotomy of capacity versus surrogacy. The purpose of this paper is to review recent empirical research that has contributed knowledge about the shared decision-making involvement of persons with dementia and their family carers.

Several theoretical perspectives presented in the 1990's emphasize the person with dementia, and precede a more recent body of research on the involvement of persons with dementia in the decision-making process. Notable contributions from social psychologist Tom Kitwood (1990), biomedical ethicist Rebecca Dresser (1992), and philosopher Agnieszka Jaworska (1999) have provided rationale for including persons with dementia and respecting their current values and preferences during the decision-making process. A fundamental assertion of Kitwood's theory is that the medical model of dementia is unnecessarily deterministic, and that social and relational losses–not progressive cognitive impairment–strip personhood from persons living with dementia (Kitwood, 1990). Dependence upon others to make decisions about everyday and medical care is an undeniable loss in one's late-life milieu, and it diminishes personhood. According to Dresser (1992), the interests of persons with dementia continue to evolve in conjunction with the effects of their illness. Consequently, their current values and preferences, as opposed to the values held prior to dementia, must be taken into account during the decision-making process (R. S. Dresser, 1992). Jaworska adds to Dresser's stance by arguing that persons with dementia are capable of decision-making involvement so long as they maintain the capacity to value, and there is nothing about the capacity to value that requires an intact memory (Jaworska, 1999). These theoretical perspectives support the practice of shared decision-making within family care dyads (dyads comprised of a person with dementia and a family carer).

Family carers' involvement in decision-making is often essential to the process of translating the values of persons with dementia into decisions. Although frustration and confusion are common reactions to care related decision-making for many older adults, persons with dementia typically face the additional challenge of doing so with impaired insight and executive dysfunction (Kensinger, 2009; Orfei et al., 2010; Sörensen et al., 2011). It is thus customary in healthcare settings to rely upon family members to make treatment and long-term care decisions for persons with dementia, regardless of whether legal or medical channels have formally established incapacity to make decisions (Kapp, 2002). Yet, the involvement of family carers in decision-making need not supersede the contributions of persons with dementia to decisions about their own care. Persons with dementia maintain the ability to communicate values and preferences long after their decision-making abilities are affected by cognitive changes. Research within the past 13 years indicates that participants can reliably report on their care values and preferences, well-being, and quality of life through moderate to severe dementia (Feinberg & Whitlatch, 2001, 2002; Karel, Moye, Bank, & Azar, 2007; Logsdon et al., 2002; Mak, 2011; Whitlatch et al., 2009). Thus, persons with dementia are able to communicate their values, but not necessarily execute a decision accordingly.

Following these theoretical and empirical developments, a number of studies have contributed to knowledge about the involvement of both the person with dementia and the family carer in the decision-making process. The goals of this paper are to: 1) review findings on the extent of shared decision-making involvement in family care dyads; 2) identify factors that prevent or promote involvement of persons with dementia; and 3) identify future research that is needed in order to better understand, and facilitate, shared decision-making by the family care dyad. Methods for determining decision-making capacity of persons with dementia will not be reviewed in this paper, but have been reviewed and described elsewhere (e.g. Arias, 2013; Karlawish, 2008; Kim et al., 2011; Moye & Marson, 2007). Additionally, this paper joins others in promoting the notion that the involvement of persons with dementia in decision-making does not necessarily end–nor does the family carer's involvement begin–with changes in the decision-making abilities of persons with dementia (O'Connor et al., 2009; Sabat, 2005).

Method

A broad search of the recent literature on decision-making in dementia, including results from all disciplines, was conducted through several databases. A scope of 15 years was established based on the theoretical and empirical developments guiding this paper. Ovid MEDLINE (1999 to July, Week 1, 2014), PsychInfo (Ovid), and CINAHL were searched using the Medical Subject Heading (MeSH) term "dementia" in combination with the MeSH terms: "decision making," and "patient participation". The searches were limited to peer-reviewed journal articles written or available in English, and publication dates between 1999 and July 2014. This strategy yielded 781 results from Ovid MEDLINE. An additional 53 non-duplicate articles were found in PsychInfo, and 16 additional non-duplicate articles from CINAHL. Hand-combing of abstracts and removal of sources that were not based upon participant data (e.g. reviews, editorials, commentary pieces) or that were focused on populations that did not pertain to dementia and family care dyads (e.g. schizophrenia, physicians) yielded 153 articles (107 MEDLINE; 30 PsychInfo; 16 CINAHL).

The next phase of the selection process involved screening for content relevant to the decision-making involvement of persons with dementia and family carers. Studies with results pertaining to the involvement of persons with dementia and their family carers in decisions about healthcare delivery, treatment, long-term care, caregiving, and everyday care were included. Studies that focused on methods for determining decision-making capacity (33) or on surrogate decision-making (38) were excluded. Also excluded were studies that focused primarily on the healthcare provider's clinical decision-making process (9), decision-making around participation in research (14), and studies regarding neurological aspects of the decision-making process (12). Finally, studies pertaining to advance directives (27) and decision-making at the end-of-life (20) were excluded. This latter criterion reflects the aim of the paper to review knowledge about the shared decision-making process between persons with dementia and family carers. A total of 33 articles met the criteria for inclusion. Reference sections from this set of articles were then examined, and an additional 3 articles that also met the inclusion criteria were chosen for the final set of 36 articles for analysis.

The final 36 articles were diverse in several ways. Most studies (20) included both persons with dementia and family carers as participants. Eight studies interviewed the family carer only regarding the decision-making process, and eight studies interviewed the person with dementia only. The majority of quantitative studies (11) used a measure of decision-making involvement, but only one of those measures (used in five studies) has been psychometrically tested among participants with dementia (see: Menne et al., 2008). Most studies (19) were qualitative, with a variety of methods including critical ethnography, phenomenology, thematic analysis, and grounded theory. Six studies were longitudinal, including one randomized controlled trial (Hilgeman et al., 2014), and the remaining were cross-sectional. Publication dates spanned 2001 to 2014.

The extent of shared decision-making involvement

Preferences and expectations of persons with dementia

Although few studies have surveyed persons with dementia about preferences for their own involvement in decision-making, many report preferences anecdotally (e.g. (Samsi & Manthorpe, 2013; Tyrrell et al., 2006). In the four known studies that have asked persons with dementia directly about their preferences for involvement in decision-making, participants (aggregate n = 249) resoundingly responded that they want to make, or to participate in, decisions regarding their own treatment and care (Hamann et al., 2011; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Karel, Gurrera, Hicken, & Moye, 2010; Karel et al., 2007). When studied over a 9-month period, the preferences of persons with dementia for their involvement in decision-making remained stable (Karel et al., 2007). Furthermore, persons with mild cognitive impairment or dementia typically identified themselves as the agents who should have the most say in decision-making around general medical issues, relocation to long-term care, and driving cessation, over and above their family carers and physicians (Adler, 2010; Hamann et al., 2011; Karel et al., 2007).

The spectrum of shared decision-making

In contrast to the preferences and expectations for decision-making involvement held by persons with dementia, the actual extent of their decision-making involvement is likely more limited. Even at levels of very mild cognitive impairment (Mini-Mental State Exam scores of 27-30), only 9% of persons with dementia (n = 7) made the final decision about their medical treatment in one study (Karlawish, Casarett, Propert, James, & Clark, 2002). In the same study, 64% of family carers (n = 48) indicated that they made the final decisions about medical care, and 26% of family carers (n = 19) indicated that they made decisions together with the person with dementia (Karlawish et al., 2002). In another study, only 44% of family carers indicated that they would involve the person with mild to moderate dementia in a decision regarding medical treatment (Hirschman, Joyce, James, Xie, Casarett, et al., 2005). The most likely scenario for persons with mild dementia is a shared decision-making process and a consensus decision with a family carer (Karlawish et al., 2002; Samsi & Manthorpe, 2013; Smebye, Kirkevold, & Engedal, 2012). For persons with moderate dementia, family carers are more likely to either check-in before making final decisions or make the final decisions alone (Karlawish et al., 2002; Samsi & Manthorpe, 2013).

The spectrum of shared decision-making also includes patterns that are more difficult to characterize. Smebye et al. (2012) identified the pattern of pseudo-autonomous decision-making, whereby family carers made decisions that they based upon assumptions of preferences rather than confirming the current choice of the person with dementia directly. Two studies identified strategies that family carers employed to give persons with dementia autonomy–labeled ‘assisted autonomy’ by Boyle (2013)–while limiting the number of options so that it would be less daunting (Boyle, 2013; Fetherstonhaugh et al., 2013). Another study found a common pattern of bridging during decision-making, which was described (by persons with dementia) as looking for ways to connect one's current life to the future through the support of carers (Keady, Williams, & Hughes-Roberts, 2009).

Perceptions of persons with dementia

For persons with dementia, the tension between relying on family carers and protecting their own agency arises frequently in the context of decision-making. Persons with dementia are able to identify consistently the person they prefer to participate in decision-making with them, and that person is most often an adult child or spouse family carer (Feinberg & Whitlatch, 2002; Karel et al., 2007). Persons with dementia also emphasize an interest in being involved in the process of making treatment decisions, rather than making the final decision, but there is a difficult balance between gaining the family carer's subtle support and having family carers take over the process completely (Fetherstonhaugh et al., 2013; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Keady et al., 2009). Many persons with dementia think that decisions should be a shared responsibility (Adler, 2010; Horton-Deutsch et al., 2007; Karel et al., 2010). Yet, persons with dementia express difficulties in achieving a shared decision-making process (Boyle, 2013; Fetherstonhaugh et al., 2013; MacQuarrie, 2005; Tyrrell et al., 2006). During the process of making a decision, some persons with dementia frequently feel that they are not being listened to by family carers, and that they are not able to express their views adequately prior to the final decision (Tyrrell et al., 2006). Similar themes identified by persons with dementia during in-depth interviews include marginalization (Boyle, 2013; Fetherstonhaugh et al., 2013), and a loss of control over their own lives (MacQuarrie, 2005).

Alternative perspectives of the perceptions of persons with dementia have also been presented. Some persons with dementia have difficulty considering their "future selves" (Dening et al., 2013), and may avoid involvement in decision-making (de Boer, Dröes, Jonker, Eefsting, & Hertogh, 2012; MacQuarrie, 2005). Although no studies in this review specifically examined the relationship between avoidance and decision-making, there is evidence that some persons with dementia fear their future cognitive decline (de Boer et al., 2012) and may interpret dementia as a threat to their autonomy (MacQuarrie, 2005). Avoidance of decisions that have the potential to conjure up these fears could be interpreted as a self-protective mechanism. Still, as a recent study indicated, persons with dementia freely express their preferences for future care when prompted, even when they also express uncertainty about participating in the decision-making process (Goodman, Amador, Elmore, Machen, & Mathie, 2013). It may be that some persons with dementia want to avoid certain aspects of the decision-making process, such as requesting to be involved, rather than avoiding the decision-making process in its entirety. There is also evidence that when persons with dementia place greater importance on maintaining their own autonomy, they also report higher levels of decision-making involvement (Menne & Whitlatch, 2007). In other words, the desire to participate in decisions is fairly universal among persons with dementia but the broader value of autonomy is not. The strength of the value of autonomy may be a better indicator of which persons with dementia will persevere with decision-making involvement.

Perceptions of family carers

Family carers accurately identify themselves as the person who the family member with dementia would want to make decisions for them about their care (Feinberg & Whitlatch, 2002). However, family carers underestimate the interest of the person with dementia in participating in decisions regarding their treatment and care (Hirschman, Joyce, James, Xie, & Karlawish, 2005), and perceive the decision-making involvement of persons with dementia to be less than persons with dementia themselves perceive their involvement to be (Feinberg & Whitlatch, 2002). Furthermore, in a study that explored family care dyads' preferences for the participation of patients with mild cognitive impairment or early Alzheimer's disease in five different decisions (three medical decisions, driving cessation, and relocation to long-term care), family carers (n = 99) preferred the patient to have significantly lower participation in all five decisions than the patients themselves (n = 100) preferred (Hamann et al., 2011).

The family carer's perception of the ability of the person with dementia to participate in decision-making is an important factor in their own decision-making process (Caron, Ducharme, & Griffith, 2006). Family carers who perceive "cognitive overload" in the person with dementia intentionally limit their involvement by reserving shared decision-making for the most important decisions (Samsi & Manthorpe, 2013), or by restricting the number of possible options from which the person with dementia can make a decision (Fetherstonhaugh et al., 2013). For example, one spouse no longer asked her husband with dementia what he wanted for dinner, in an attempt to reduce the burden of making minor decisions (Samsi & Manthorpe, 2013). Finally, the family carer's perception of the extent of the involvement of persons with dementia in decisions may have other repercussions. Family carers who perceive persons with dementia as being more involved in everyday decision-making are also more congruent in their perceptions of the everyday care values held by the person with dementia (Reamy et al., 2011). This finding seems to be indicative of the importance of the family carer's perception of shared decision-making to the cohesion of the family care dyad.

Determinants of shared decision-making involvement

Cognitive Impairment

Persons with dementia are more likely to be involved in decision-making when the dementia diagnosis is new or recent (Hirschman, Xie, Feudtner, & Karlawish, 2004; Menne & Whitlatch, 2007), when they have greater insight into their condition (Hirschman, Joyce, James, Xie, & Karlawish, 2005), and when the stage of dementia is mild (Hirschman, Joyce, James, Xie, Casarett, et al., 2005; Karlawish et al., 2002; Menne et al., 2008). Shared decision-making typically occurred when the person with dementia scored 20 or above on the Mini-mental State Exam (MMSE) (Folstein, Folstein, & McHugh, 1975) in two studies of family care dyads (Hirschman et al., 2004; Karlawish et al., 2002). In a longitudinal study of 77 family care dyads, once the scores of the participants with dementia dropped to between 12 and 19 on the MMSE, family carers were more than twice as likely (OR = 2.35, 95% CI = 1.01, 5.49) to take a dominant or exclusive role in decision-making compared to when scores were 20 and above, controlling for age of the participants with dementia and the family carers' burden (Folstein, Folstein, & McHugh, 1975; Hirschman et al., 2004). Thus, the extent of decision-making involvement of persons with dementia declines in tandem with the progression of dementia.

Demographic factors

The demographic characteristics of family care dyads who participate in shared decision-making involvement appear to be different from those of the dyads who do not share involvement. Higher levels of education (greater than 12 years) have a positive association with decision-making involvement of persons with dementia (Hirschman, Joyce, James, Xie, Casarett, et al., 2005; Menne & Whitlatch, 2007). Older age in either the person with dementia or the family carer is negatively associated with shared decision-making (Hirschman et al., 2004; Menne et al., 2008). Controlling for MMSE score and family carer burden, each year of increase in age of participants with dementia was associated with a 6% decrease in the odds (OR 1.06, 95% CI = 1.00 – 1.12) of shared decision-making involvement in a longitudinal study of 77 family care dyads (Hirschman et al., 2004).

Gender also appears to influence decision-making involvement, albeit in opposite directions across studies. Some report that males with dementia were more likely to remain involved in medical decision-making (Hirschman, Joyce, James, Xie, Casarett, et al., 2005), and in financial decision-making (Boyle, 2013). In two other studies (same sample) of everyday care decisions such as eating and dressing, females with dementia had a greater likelihood of decision-making involvement (Menne et al., 2008; Menne & Whitlatch, 2007). Family carer gender may also influence shared decision-making. Female family carers were associated with greater involvement of persons with dementia in two studies (same sample pool) (Hirschman, Joyce, James, Xie, Casarett, et al., 2005; Hirschman, Joyce, James, Xie, & Karlawish, 2005), and dyads with male family carers were associated with greater decision-making involvement of persons with dementia in two other studies (Menne et al., 2008; Menne & Whitlatch, 2007). The conflicting direction of influence of gender on decision-making involvement may be due in part to the types of decisions. As Menne et al. discussed (2008), females who typically made many of the everyday household decisions (e.g. what food to buy and eat at meals) prior to developing dementia, would likely remain involved to a greater extent than the males who never were involved in those decisions. Likewise, in many traditional households with only the male earning the family income, males may maintain involvement in financial decisions for a longer period after becoming cognitively impaired. To explore this conflict further, future studies will need to compare the decision-making process in families before and after a dementia diagnosis.

The type of kinship between the person with dementia and family carer also influences decision-making involvement. Spouses in three studies (same sample pool) were more likely than adult children to involve persons with dementia in decisions about their treatment and care (Hirschman, Joyce, James, Xie, Casarett, et al., 2005; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Hirschman et al., 2004). In the first study, spouse family carers were 2.57 times as likely as adult child family carers to participate in shared decision-making involvement with persons with dementia (OR = 2.57, 95% CI = 1.12 – 5.90), although the analysis did not control for other risk factors, such as relationship quality (Hirschman et al., 2004). The second study controlled for the MMSE score of the person with dementia and the family carer's gender, and found spouse carers to be 7.58 times as likely as adult children carers to involve persons with dementia in decision-making around medical treatment (OR = 7.58, 95% CI = 2.25 – 25.54) (Hirschman, Joyce, James, Xie, Casarett, et al., 2005). One explanation given was that spouse carers know the person with dementia better, and may work harder to be engaged and find effective approaches to communicating (Hirschman, Joyce, James, Xie, & Karlawish, 2005). Further work that includes both kinship type and the quality of the relationship is needed to untangle these findings.

Modifiable factors

Few studies have examined whether modifiable factors influence the involvement of persons with dementia in the decision-making process. In one study, poorer quality of life in the person with dementia, depression in the family carer, and negative relationship strain were negatively associated with decision-making involvement of the person with dementia (Menne et al., 2008). Family carer burden was associated with less decision-making involvement among participants with dementia in two earlier studies (Hirschman et al., 2004; Karlawish et al., 2002). In a longitudinal qualitative study of family care dyads, persons with dementia and family carers described their strategies to maintain the autonomy of the person with dementia, but the impact of their efforts on decision-making was not reported (Samsi & Manthorpe, 2013). As mentioned earlier, the accuracy of the family carer's perception of the values and preferences of the person with dementia was associated with greater involvement of persons with dementia in decision-making in several studies (Reamy et al., 2011; Whitlatch et al., 2005b; Whitlatch et al., 2009). According to Reamy et al. (2011), one explanation for this finding may be related to the likelihood that a carer who is supportive of shared decision-making is also more adept at deciphering the values of the person with dementia. The relationship between shared decision-making and the carer's perception of care values could have important implications for interventions to improve the accuracy of surrogate decision-making in later stages of dementia, or to reduce incongruence among family care dyads.

Factors related to diagnosis and care planning

Some persons with dementia lose the chance to be involved in decision-making entirely when their dementia diagnosis is not openly disclosed to them (Laakkonen, Raivio, Eloniemi-Sulkava, Tilvis, & Pitkala, 2008), or when a diagnosis is difficult to obtain during the early stages of disease (Adler, 2010). Family carers also report that they feel pressured by health care providers and case managers to take charge and make decisions with or without input from the patient with dementia (Couture, Ducharme, & Lamontagne, 2012; St-Amant et al., 2012). Time-specific hindrances were identified in several qualitative studies, including a lack of early discussions with persons with dementia and failure to explore options together while all the options are still available (Adler, 2010; Horton-Deutsch et al., 2007; St-Amant et al., 2012; Wolfs et al., 2012). Although these qualitative studies provide rich detail of the experiences of family carers, quantitative studies that build on this important work, control for other influential factors, and include larger, more representative samples are needed.

Types of decisions

Everyday care

Seven studies included in this review specifically considered everyday care decisions, such as grooming, socializing, eating, and spending money (Adler, 2010; Boyle, 2013; Feinberg & Whitlatch, 2002; Menne et al., 2008; Menne & Whitlatch, 2007; Reamy et al., 2011; Samsi & Manthorpe, 2013). Notably, four of the seven studies used versions of a measure for decision-making involvement of persons with dementia that is the only known measure of decision-making to be developed for the family care dyad (Feinberg & Whitlatch, 2002; Menne et al., 2008; Menne & Whitlatch, 2007; Reamy et al., 2011). The current Decision-Making Involvement (DMI) Scale includes 15 items that consider everyday decisions such as what foods to buy, what to do in spare time, and when to go to bed (Menne et al., 2008). On a 0 to 3 scale (0= not at all involved, 3= very involved) persons with dementia across three studies rated their decision-making involvement, on average, to be 1.89 (SD =.60) to 2.30 (SD = .59), whereas family carers rated the involvement of persons with dementia in everyday decisions to be 1.67 (range = .33 to 2.73) to 1.88 (SD = .76) (Feinberg & Whitlatch, 2002; Menne et al., 2008; Menne & Whitlatch, 2007). Additionally, two of these studies measured discrepancies within family care dyads' ratings and found that persons with dementia perceived their own involvement in decision-making about everyday care to be significantly greater than family carers perceived the involvement of the person with dementia (Feinberg & Whitlatch, 2002; Menne et al., 2008).

Qualitative findings further articulate the patterns of everyday decision-making in family care dyads. A phenomenological study of 12 family care dyads examined the changing dynamics of everyday decision-making in the home (Samsi & Manthorpe, 2013). Over time, all dyads moved progressively toward substituted decision-making by the family carer, but the majority of dyads deliberately attempted to support the autonomy of the person with dementia (Samsi & Manthorpe, 2013). Attempts to support autonomy ranged from limiting options and providing decision-making cues to restricting the types of decisions to the most important ones (Samsi & Manthorpe, 2013). An ethnographic study of 21 English family care dyads examined the involvement of persons with dementia in financial decision-making, and found most family carers had taken over entirely, including decisions about how to spend money on a day-to-day basis (Boyle, 2013). The few persons with dementia who retained financial decision-making autonomy were also primarily responsible for these decisions prior to dementia (Boyle, 2013). Some couples had taken particular steps to maintain financial autonomy among persons with dementia in everyday situations, such as arranging for payment on credit at local stores (Boyle, 2013). Still, most persons with dementia became excluded from the financial decision-making process after a dementia diagnosis, regardless of their ability to remain involved (Boyle, 2013).

Medical treatment

Seven studies included in this review specifically considered the medical and healthcare decision-making process (Hirschman, Joyce, James, Xie, Casarett, et al., 2005; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Hirschman et al., 2004; Horton-Deutsch et al., 2007; Karel et al., 2010; Karel et al., 2007; Karlawish et al., 2002). Persons with dementia prefer a healthcare decision-making process that is shared between their family carer, doctor, and themselves (Hirschman, Joyce, James, Xie, & Karlawish, 2005; Karel et al., 2010; Karel et al., 2007), whereas the majority of family carers indicated that they would make the final medical decisions alone and may or may not involve the person with dementia in the process (Hirschman, Joyce, James, Xie, Casarett, et al., 2005; Karlawish et al., 2002). In the two studies that included both members of the dyad, incongruence in preferences for and perceptions of the medical decision-making process were apparent, with persons with dementia favoring more involvement and perceiving actual involvement as higher than family carers perceived or anticipated involvement of persons with dementia to be (Hirschman, Joyce, James, Xie, & Karlawish, 2005; Horton-Deutsch et al., 2007). It is worth noting that none of the seven studies took place in an inpatient setting. All participants completed surveys during an outpatient clinic visit or at home.

Long-term care placement

Very few studies examined the involvement of persons with dementia in the decision-making process surrounding long-term care. Only two long-term care decision-making studies could be found that included persons with dementia as participants (St-Amant et al., 2012; Tyrrell et al., 2006). In a longitudinal ethnographic study of 9 persons with dementia, their family carers, and case managers from long-term care settings, St.-Amant et al. (2012) described a lack of involvement of the person with dementia in the decision-making process, and a reliance on an oversimplified notion of incompetence in persons with dementia as a contributing factor. Despite family carers' intention to make decisions that were congruent with the wishes of their family member with dementia, they prematurely excluded the person with dementia from conversations about placement in order to accommodate this dichotomous notion of incompetence versus competence (St-Amant et al., 2012). Case managers also felt it was their legal duty to focus on the decision of the individual who was named as a surrogate decision-maker and even exclude the person with dementia from the conversation, rather than entertain a variety of perspectives (St-Amant et al., 2012). In another qualitative study of 21 French family care dyads, Tyrell et al. (2006) found that most persons with dementia did not feel that they were able to adequately express their views about a long-term care placement or home care service decision, and all but one participant with dementia thought that the decision was made without sufficient time for reflection. Although an aggregate of only 30 persons with dementia participated in these two studies, the findings are consistent with each other and also with the reports from the family carer participants.

Family carers were interviewed in an additional five studies about the decision-making process for long-term care placement of a relative with dementia (Butcher, Holkup, Park, & Maas, 2001; Caldwell, Low, & Brodaty, 2014; Caron et al., 2006; Chang & Schneider, 2010; Couture et al., 2012). In all of these studies, family carers were the instigators of the decision-making process for long-term care (Butcher et al., 2001; Caldwell et al., 2014; Caron et al., 2006; Chang & Schneider, 2010; Couture et al., 2012). However, it was unclear whether it was an assumption of the studies that carers would be making long-term care placement decisions alone, which could have led to recruitment of carers for whom this was already true.

The primary family carer often involves other family members as well as health care professionals in the difficult process of deciding upon long-term care (Caldwell et al., 2014; Caron et al., 2006; Chang & Schneider, 2010; Couture et al., 2012). The role of the person with dementia in the process was either unspecified or nonexistent in all five carer studies. In one study, family carers believed that decision-making capacity limited the participation of the person with dementia in decisions surrounding long-term care placement, and in choosing placement over home-based care (Caron et al., 2006). Another study identified health care professionals as gatekeepers for involvement of persons with dementia in conversations around placement decisions (Couture et al., 2012). Regardless of the underlying reasons, the overarching message taken from this group of studies is that persons with dementia do not seem to be involved in decisions surrounding their own placement in long-term care. This message could reflect the types of participants involved in these studies, namely family carers of persons who are more severely impaired by or exhibiting more symptoms of dementia. Alternatively, it could reflect the reality that most persons with dementia do not want to live in a nursing home (Feinberg & Whitlatch, 2002), and thus the decision to end home care may indeed rest with the family carer.

Interventions

Several interventions with outcomes intended to improve the shared decision-making process among family care dyads have been published within the last eight years (Hilgeman et al., 2014; Murphy & Oliver, 2013; Silverstein & Sherman, 2010; Whitlatch, Judge, Zarit, & Femia, 2006). Most recently, Hilgeman et al. (2014) completed a pilot randomized controlled trial of a patient-centered intervention to improve emotional and health-related outcomes of 19 patients with mild dementia and their family carers. The intervention group exhibited significant decreases in decisional conflict compared to the control group, as well as a clinically meaningful decrease in depression and better quality of life (Hilgeman et al., 2014). Promising results were also reported in Whitlatch et al.'s (2006) dyadic counseling intervention, where 31 family care dyads successfully participated in up to nine sessions focusing on values and preferences for future care. The intervention was determined to be feasible and acceptable, and useful for involving both members of the dyad in communicating about present and future care decisions (Whitlatch et al., 2006). Silverstein and Sherman (2010) conducted an educational intervention targeting family carers of persons with dementia, which resulted in positive impacts on the feelings of the person with dementia about their participation and on the family carer's perception of the decision-making process. Finally, Murphy and Oliver (2013) tested the effectiveness of a communication aid called "Talking Mats" in improving decision-making among 18 family care dyads, and found that the intervention improved the perceived involvement in decision-making among both persons with dementia and family carers.

Discussion

The existing body of empirical literature concerning the decision-making process of family care dyads indicates that not all persons with dementia are excluded from participating in the decision-making process, but there is a broad spectrum of what may constitute shared decision-making in dementia. Although none of the 36 studies included in this review provided an explicit definition for shared decision-making in dementia, the defining feature was the amount or type of the involvement of the person with dementia in the process. Qualitative studies identified diverse patterns of the involvement of the person with dementia. Some patterns related to the modifications a carer made to support the autonomy of the person with dementia, including assisted or supported autonomy (Boyle, 2013; Samsi & Manthorpe, 2013) and ‘pseudo-autonomous decisions’ (Smebye et al., 2012). Other patterns related to the wide range of positions occupied by the person with dementia in the decision-making process: being free to make a choice (Tyrrell et al., 2006), being a decision-making agent (MacQuarrie, 2005), being central to the process (Fetherstonhaugh et al., 2013), being in or out of balance with carers (Keady et al., 2009), being listened to by carers (Tyrrell et al., 2006), or being reliant upon carers (Horton-Deutsch et al., 2007). Similarly among the quantitative studies in this review, the level of involvement ranged from a dichotomous involved/not involved (Hirschman, Joyce, James, Xie, Casarett, et al., 2005) to a categorical gradient of the person with dementia making final decisions, participating equally in final decisions, or participating but carers making final decisions (Karlawish et al., 2002). Thus, any type or amount of involvement of persons with dementia currently constitutes shared decision-making in dementia.

Although most persons with dementia report wanting to participate in shared decision-making with their family carers, many do not remain involved once their symptoms move beyond mild dementia. As two of the longitudinal studies in this review concluded, shared decision-making is a continuum on which the involvement of the person with dementia declines over time and in tandem with cognitive function (Hirschman et al., 2004; Samsi & Manthorpe, 2013). According to theoretical positions and empirical evidence demonstrating the reliability and consistency of the person with dementia in self-reporting values and preferences, the severity of cognitive impairment alone should not be the determining factor of involvement in decision-making. Yet, as several studies indicated, the severity of cognitive impairment is strongly correlated, and even predictive of, lower levels of decision-making involvement. Although the views of family care dyads regarding this phenomenon have yet to be explored, increasing severity of cognitive impairment likely manifests in ways that are more apparent to family carers, which may lead carers to believe that it is necessary or beneficial to assume control on their behalf.

Shared decision-making involvement also varies according to certain demographic characteristics (education, age, gender, and type of kinship), psychosocial issues (quality of life, depression, relationship strain, and carer burden), and the context and nature of the decision at hand. Future research should focus on factors that are modifiable. Control variables such as cognitive impairment and gender have been documented by previous studies, and help identify family care dyads who need additional help in maintaining a shared decision-making process. However, additional research on modifiable factors is needed to further develop interventions to improve the involvement of persons with dementia in decision-making.

Family carers recognize the need to increase their own involvement in decision-making as the decision-making ability of the person with dementia declines, but findings from this literature review indicate that persons with dementia may be prematurely excluded from the process of making a variety of care decisions. The consequences of this premature exclusion are great. When family carers perceive that persons with dementia are more involved in decisions, family carers have better quality of life, less depression, less negative strain, and are more congruent in their understanding of the values of the person with dementia (Menne et al., 2008; Reamy et al., 2011). For persons with dementia, being a part of the decision-making process may hold a grander meaning of validating their very existence or personhood, regardless of the outcome or who makes the final decision (Fetherstonhaugh et al., 2013). The process of decision-making is likely of as much if not more importance to family care dyads than the outcomes.

In reviewing the existing body of literature on shared decision-making involvement among family care dyads, it is apparent that additional research is needed that reflects the perspective of persons with dementia, especially concerning the processes surrounding decision-making in the acute care setting and regarding placement in long-term care settings. Studies concerning everyday care decisions were exceptional in that all seven included both members of the family care dyad. The process for making medical treatment decisions has been examined from both perspectives of the dyad to some extent, but no studies could be found that took place in an acute care or inpatient hospital setting, where the majority of major medical treatment decisions are made. Studies examining long-term care placement suggested that carers are responsible for the majority of this particular decision-making process. However, considering that the seven studies focusing on the process of long-term care decision-making did not explore the extent of involvement of persons with dementia, it is unclear whether they are simply not very involved or whether family carers of relatives with more severe dementia (thus limiting participation) were overrepresented. It may be the case that this particular decision is more difficult for the dyad to broach, and if persons with dementia view placement negatively, family carers may feel compelled to make the decision without their input. Future research could untangle these questions by including family carers of persons with early dementia, and by comparing involvement across different types of decisions to determine whether long-term care placement is indeed decided with less involvement from persons with dementia.

Until recently, much of the dementia decision-making literature has focused on either the assessment of decision-making capacity of the person with dementia or the role of the surrogate decision-maker. Early diagnosis of Alzheimer’s disease and other dementias will continue to extend the time in which families have to prepare for decisions about everyday, medical, and long-term care. A shared decision-making process provides opportunities for both the person with dementia and the family carer to be involved and to express values or preferences related to specific decisions. The body of literature on shared decision-making in dementia reveals that persons with dementia are involved to varying degrees, but most are prematurely excluded from decision-making due to disease-specific and non-modifiable risk factors. Clinicians should offer support of shared decision-making to all family care dyads, since cognitive impairment is a major risk factor for exclusion from decision-making. Additional support should be offered to adult children carers, especially when carer burden, relationship strain, or depression in either the person with dementia or the family carer is evident. Future research uncovering additional modifiable risk factors will help with the development of interventions targeted at family care dyads who need the most help in maintaining both members’ involvement.

CHAPTER III

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

Proposed Authors: Lyndsey M. Miller, Christopher S. Lee, Carol J. Whitlatch, and Karen S. Lyons

This manuscript represents a significant contribution to the dissertation work, and replaces aspects of the traditional results and discussion chapters. The target journal for this manuscript's submission is *The Gerontologist,* a peer-reviewed bi-monthly journal that provides a multidisciplinary perspective on human aging through the publication of research and analysis in gerontology, including social policy, program development, and service delivery.

Abstract

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

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

Results: Both members of the dyad rated the PWD, on average, as being "somewhat involved". There was a significant amount of variability around the average perceptions of PWD involvement in decision-making for both PWDs ($\chi^2 = 351.02$, $p < .001$) and family caregivers ($\chi^2 = 327.01$, $p < .001$). Both PWDs and family caregivers were significantly more likely to perceive greater PWD involvement in decision-making when the family caregiver reported the PWD as valuing autonomy. Additionally, PWDs were significantly more likely to report greater involvement when they had greater cognitive function. Finally, family caregivers perceived significantly greater involvement of the patient in decision-making when they reported less strain in the relationship. Together, autonomy, relationship strain, cognitive function, and care-related strain accounted for 38% and 42% of the variability in PWDs' and family caregivers' perceptions, respectively, of the PWD's decision-making involvement.

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

The continued involvement of a person with dementia (PWD) in decision making is an important goal for both the PWD and the family caregiver (Fetherstonhaugh et al., 2013; Samsi & Manthorpe, 2013). Although researchers have often examined the involvement of PWDs in medical and treatment decisions (Hirschman et al., 2004; Horton-Deutsch et al., 2007; Karel et al., 2010; Karlawish et al., 2002), it is the involvement in "everyday" decisions about daily care, activities, and functioning that is often most important to PWDs (Feinberg & Whitlatch, 2002; Menne & Whitlatch, 2007; Murphy & Oliver, 2013; Samsi & Manthorpe, 2013). Involvement in these everyday decisions give the PWD a sense of purpose and help them to avoid feeling marginalized (Fetherstonhaugh et al., 2013). There is also evidence that there are fewer depressive symptoms in the family caregiver and better quality of life in both PWD and family caregiver when the PWD is more involved in everyday decision making (Menne, Judge, & Whitlatch, 2009; Menne et al., 2008; Samsi & Manthorpe, 2013).

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

Dementia is a shared context for the PWD-family caregiver dyad. A dyadic perspective (PWD and family caregiver as a unit) is important to the understanding of decision making about everyday aspects of life with dementia, particularly since the lives of this type of care dyad are so intertwined (Samsi & Manthorpe, 2013). Whereas the family caregiver's perspective has historically been used in research to represent the PWD (Cotrell & Schulz, 1993), the PWD's perspective is important to include because involvement of PWDs in decision making is important to the family caregiver and it is also associated with better quality of life for the dyad (Menne et al., 2009; Menne et al., 2008; Samsi & Manthorpe, 2013). Furthermore, including the PWD's perspective is important to maintaining personhood (Bartlett & O'Connor, 2007; Woods, 2001), and it is warranted given the evidence supporting the reliability of PWDs' self-report. For example, PWDs have consistently and reliably reported on their own quality of life (Logsdon, Gibbons, McCurry, & Teri, 2002), well-being (Mak, 2011), depressive symptoms (Parmelee, Lawton, & Katz, 1989), and care values and preferences (Whitlatch et al., 2005), even with a moderate amount of cognitive impairment. At the same time, impairments to executive function and insight, which are common in dementia, affect PWDs' abilities to make decisions independently (Kensinger, 2009; Orfei et al., 2010; Sörensen et al., 2011), and as a result, family caregivers' are often required to make the crucial link between what a PWD values and the particular decisions at hand (Gillick, 2013). Thus, when considered together as a dyad, the two perspectives allow for an examination of decision making that reflects the joint involvement of PWD and family caregiver that is often necessary and optimal in the context of dementia.

Conceptual Framework

In order to represent both dyad members' perspectives conceptually, the framework for this study is derived from the Stress Process Model (SPM) for family caregivers of PWDs (Pearlin et al., 1990), as well as subsequent versions that have been operationalized for individuals with chronic illness (Menne & Whitlatch, 2007), and more recently, for persons with dementia (Judge, Menne, et al., 2010). The three iterations share in common a model encompassing primary stressors and secondary strains that are influential upon one another and together on an outcome of wellbeing such as quality of life or depression (Pearlin et al., 1990), or decision-making involvement of PWDs (Menne & Whitlatch, 2007). The three main components that influence such outcomes are: 1) primary stressors related to dementia/dementia caregiving, both objective (e.g. pathologies of the disease) and subjective (e.g. overload of care tasks or psychological distress of living with dementia), 2) secondary role strains (i.e. strains that occur as a result of adapting to life with dementia), and 3) secondary intrapsychic strains, described by Pearlin et al. (1990) as strains on "dimensions of self-concept" (e.g. self-esteem).

In the conceptualization of stressors and strains for this study we drew upon the three versions of the SPM (Judge, Menne, et al., 2010; Menne & Whitlatch, 2007; Pearlin et al., 1990) and integrated them with the resulting literature to maintain a dyadic perspective of the illness experience. Thus, we operationalized the primary objective stressor related to the dementia illness experience as cognitive function (Judge, Menne, et al., 2010; Pearlin et al., 1990), the primary subjective stressor as care-related strain (Menne et al., 2009; Pearlin et al., 1990), the secondary role strain as dyadic relationship strain (Judge, Menne, et al., 2010; Menne & Whitlatch, 2007; Sebern & Whitlatch, 2007), and the secondary intrapsychic strain as the importance of autonomy to the PWD (Menne et al., 2009; Menne & Whitlatch, 2007). Other studies outside the SPM literature have also shown that cognitive impairment and care-related strain are significantly associated with the family caregiver's perception of the PWD's decision-making involvement (Hirschman et al., 2004; Karlawish et al., 2002). Few studies, however, have examined the PWD's involvement in everyday decision-making from both perspectives (Adler, 2010; Boyle, 2013; Menne & Whitlatch, 2007; Samsi & Manthorpe, 2013) and no prior studies have focused on decision-making of the dyad during hospitalization–an event that often calls into question aspects of the PWD's independence (e.g. activities of daily living) and the dyad's life at home (e.g. the care arrangement).

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

Methods

Participants for this study were recruited from adult inpatient acute care units in a university hospital in the Pacific Northwest. Approval was obtained from the Institutional Review Board for this study. A convenience sample of 42 dyads was enrolled that met the following eligibility criteria. **Inclusion criteria**. PWDs were eligible if they were age 65 or older, admitted to an acute care unit, had symptoms consistent with mild to moderate dementia, and self-reported a probable or current diagnosis of an irreversible progressive dementia:

Alzheimer's disease, vascular dementia, Lewy body dementia, or frontotemporal dementia. Family caregivers were eligible if they were age 21 or older, nominated by the PWD as the primary family caregiver (primary family caregiver was defined as the family member who is most involved in care at home). To be eligible, PWDs had to score at least 13 (moderate dementia) on the Mini-Mental State Exam, which corresponds to reliable, consistent reporting in previous studies using this criterion (Feinberg & Whitlatch, 2001; Logsdon et al., 2002; Parmelee et al., 1989; Whitlatch et al., 2005b). **Exclusion criteria.** Dyads were ineligible if either the PWD or family caregiver was unable to speak English, or if the PWD had unresolved delirium or altered level of consciousness, which was assessed by the direct care registered nurse (RN) prior to screening for interest.

After the investigator screened patient records for potentially eligible participants (confirming dementia diagnosis through chart review), the PWD's direct care RN screened patients and family caregivers for interest in the study. If PWD and family caregiver were interested, the researcher met with each member of the dyad to confirm interest, assess eligibility, and obtain informed consent. Individual members of each dyad completed one private interview in-person within the acute care unit (without the other member of the dyad present). Participants were provided with written cards to aid memory about response scales and answered verbal questions from the researcher. Responses were recorded by the researcher on a laptop using RedCap.

Measures

Decision-making involvement of the PWD was measured in PWDs and family caregivers using equivalent versions of the Decision-Making Involvement Scale developed specifically for the dementia care dyad (Menne et al., 2008). The measure consists of 15 items, scored on a 4-point scale: 0 = not involved at all, 1 = a little involved, 2 = somewhat involved, 3 = very involved. Each member of the dyad responds with their perceptions of how involved the PWD is in everyday types of decisions (e.g. what to eat at meals, choosing places to go) and item scores are averaged for a total scale range of 0 to 3 with higher scores indicating more PWD decision-making involvement. This measure has previously been used among older adults with cognitive impairment and their family caregivers, with established validity and reliability (Menne et al., 2008; Reamy et al., 2011). The reliability in this study was excellent (PWD α = .89; family caregiver α = .87).

Cognitive status was screened and measured in PWDs with the 11-item Mini-Mental State Examination (MMSE) (Folstein et al., 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 person with dementia. 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 (α = .75)

Relationship strain was measured in family caregivers using the 5-item Dyadic Strain subscale of the Dyadic Relationship Scale (Poulshock & Deimling, 1984; Sebern & Whitlatch, 2007). Each item is a statement of a potential source of strain in the relationship, for which family caregivers rate their level of agreement from 1 (strongly disagree) to 4 (strongly agree). Example items are: “Because of helping my family member, I feel angry toward her/him.” Items are averaged for a scale range of 1 to 4, with higher scores indicating more perceived relationship strain. Content, discriminant, and convergent validity of this scale have been established among caregiving dyads (Sebern & Whitlatch, 2007). The reliability in this sample was good (α = .85).

The PWD’s value of autonomy was measured in family caregivers using the autonomy subscale of the Care Values scale developed specifically for caregiving dyads in which the care recipient is a person with cognitive impairment (Whitlatch et al., 2009). The autonomy subscale has 7 items that describe a care value around autonomy (e.g. do things for him/herself). The items are rated according to the importance of each value to the PWD on a 3-point scale: 1= not at all, 2= somewhat, 3= very. The total score is averaged for a scale range of 1 to 3, with higher scores indicating that the family caregiver perceives the PWD to place more importance on their autonomy. The reliability in this sample was adequate α = .79).

Analytic Approach

Analysis of the dyadic data was conducted using multilevel modeling and the software program HLM, version 7 (Raudenbush, Bryk, & Congdon, 2011). The multivariate outcomes model (separate PWD/family caregiver outcomes) can be achieved using multilevel modeling while still estimating and controlling for the degree of shared variance in the dyad. In this study, level 1 data included PWDs and family caregivers, which were nested within the level 2 PWD-family caregiver dyad (the unit of analysis). The level 1 model estimated the average values and the variability around the averages for both the PWD's and family caregiver's perceptions of the PWD's decision-making involvement. Predictors were introduced in level 2 to explain the variability around the average. The ability to examine this variability and go beyond group differences is a distinct advantage of multilevel modeling.

Level 1 model. Within-dyad variation was modeled at level 1, where the outcome is the sum of the true score and measurement error. In the equation,

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

Decision_{ij} represents the outcome parallel score i in dyad j. PWD is an indicator variable taking on a value of 1 if the response was obtained from the PWD, or taking on a value of 0 if the response was obtained from the family caregiver. Similarly, CG is an indicator variable taking on a value of 1 if the response was obtained from the family caregiver, or taking on a value of 0 if the response was obtained from the PWD. The latent true scores of perceptions of the PWD's decision-making involvement for PWDs and family caregivers are represented by β_{1j} and β_{2j}, respectively. Error is represented as r_{ij}. Thus, PWDs' average perceptions of their own decision-making involvement (Decision) is the sum of their latent true score (β_{1j}) and measurement error (r_{ij}); or, family caregivers' average perceptions of PWDs' decision making involvement (Decision) is the sum of their latent true score (β_{2j}) and measurement error (r_{ij}). The tau correlation is also calculated at level 1 to indicate the correlation between PWDs' and family caregivers' scores of the PWD's decision-making involvement. Parallel scales were constructed for the outcome measure of decision-making involvement according to procedures previously described by Raudenbush, Brennan, & Barnett (1995) and Sayer & Klute (2005).

Level 2 model. Between-dyad variation was modeled at level 2. Based on the SPM and supporting literature from studies previously conducted in the community setting, independent variables were included in level 2 models where the parameters for latent true scores of PWDs (β_{1j}) and family caregivers (β_{2j}) become the outcome variables.

Results

Patients with dementia were mean age 80±8 years, predominantly non-Hispanic white ethnicity/race (95%), had an average MMSE score of 21±4, and a slight majority (55%) were male. The most common dementia diagnosis among patients was Alzheimer's disease (40%), followed by vascular dementia (29%), mixed or unknown dementia type (24%), fronto-temporal dementia (5%), and Lewy body dementia (2%). Family caregivers were age 61±13 years, predominantly non-Hispanic white ethnicity/race (93%), mostly female (75%), and were either adult children (70%) or spouses (30%) of patients. See Table 2 for additional demographic and descriptive data.

At Level 1, average ratings of the PWD's decision-making involvement were $\beta_{1j} = 2.11 \pm 0.10$, $p < .001$ and $\beta_{2j} = 2.09 \pm .10$, $p < .001$ for PWDs and family caregivers, respectively, indicating that, on average, both members of the dyad perceived the PWD as being "somewhat" involved in everyday decisions. The tau correlation between PWD and family caregiver ratings of the PWD's decision-making involvement was high at .76. There was a significant amount of variability around the average perceptions of PWD involvement in decision-making from the perspective of both PWDs ($\chi^2 = 351.02$, $p < .001$) and family caregivers ($\chi^2 = 327.01$, $p < .001$).

Based on Level 2 results, both PWDs and family caregivers were significantly more likely to perceive greater PWD involvement in decision-making when the family caregiver reported the PWD as valuing autonomy (see Table 3). PWDs were also significantly more likely to report greater involvement when they had better cognitive function. Family caregivers were also significantly more likely to report greater PWD involvement when they perceived less strain in their relationship with the PWD. Together, autonomy, relationship strain, cognitive function, and care-related strain accounted for 38% and 42% of the variability in PWDs' and family caregivers' perceptions, respectively, of the PWD's decision-making involvement.

Discussion

The current study was a dyadic examination of the decision-making involvement of PWDs in everyday types of decisions, and it is one of the first such studies known to include hospitalized PWDs and their family caregivers. There are several important findings. First, PWDs and family caregivers shared similar average ratings of the PWD as being "somewhat" involved in decision making, which is comparable to studies of dyads in the community setting (Menne & Whitlatch, 2007). Second, there was significant variability around the average perceptions for both PWDs and family caregivers, making the use of a method such as MLM necessary in order to further examine this variability and providing evidence that there is heterogeneity across dyads. Third, several determinants chosen according to the SPM were identified as being significantly associated with the variability in perceptions of the hospitalized PWD's decision-making involvement. This finding indicates that dyads' appraisals of the PWD's involvement in decision-making may be affected by the stress process. Finally, determinants differed across PWD/family caregiver models, reinforcing the need for a dyadic examination of decision making within the care dyad with dementia.

The family caregiver's perception of the PWD's value of autonomy was a significant determinant of both PWD and family caregiver ratings of the PWD's decision-making involvement. According to the SPM, the diminishing value of autonomy in the PWD can place an intrapsychic strain on perceptions of the PWD's involvement in making decisions, potentially lowering both PWD and family caregiver ratings (Menne & Whitlatch, 2007). As other researchers have pointed out, preserving autonomy in PWDs and supporting their involvement in decision-making are related goals (Fetherstonhaugh et al., 2013; Menne et al., 2008; Samsi & Manthorpe, 2013). However, in this study we included the family caregiver's perception of how important autonomy is to the PWD, the difference being that we measured the *value* of autonomy rather than a perception of how much independence remains in the PWD. This difference is critical since dementia continually threatens autonomy, but may not diminish how important autonomy is to a PWD. Recent perspectives on achieving person-centered care underscore the importance of moving away from how to compensate for what PWDs cannot do, and instead focus on how to promote the PWD's contributions and identity (Vernooij-Dassen & Moniz-Cook, 2016). Working with family caregivers to understand and support PWDs in their value of autonomy may be an important protective factor helping to prolong PWDs' decision-making involvement.

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

We found support in this study for the conceptualization of cognitive impairment as a primary stressor on PWDs' perceptions of their decision-making involvement, as described previously in the SPM literature (Judge, Menne, et al., 2010; Pearlin et al., 1990). Previous studies conducted in the community setting have also demonstrated that PWDs' perceptions of their decision-making involvement were higher when the PWD had greater cognitive function (Karlawish et al., 2002; Menne et al., 2008). A recent literature review of dementia decision making found that across six studies, the severity of cognitive impairment was strongly correlated, and even predictive of, lower levels of the PWD's decision-making involvement (Miller, Whitlatch, & Lyons, 2014). However, in this study family caregivers did not associate the PWD's decision-making involvement with cognitive ability, indicating that cognitive impairment may not be as influential on family caregivers' perceptions as it is on PWDs' perceptions when other influential stressors and strains (i.e. relationship strain) are included in the analyses. The PWDs included in this study had mild to moderate dementia, with an average MMSE score of 21±4. Whereas PWDs' cognitive function may weigh on their own perceptions of their decision-making involvement from early in the disease process, family caregivers' perceptions may not be significantly affected by cognitive function until the extent of impairment is greater and more observable (e.g. moderate to severe dementia).

This study was limited in its generalizability by small sample size and lack of diversity. Sample size also dictated that fewer independent variables be entered into models, which meant that only one variable could be chosen to represent each type of stressor or strain from the SPM. Yet, there were also notable strengths to the study, including the novel hospital setting, dyadic measures and data collection, and an analytic approach (i.e. MLM) appropriate for dyadic data. By including the perspective of both members of the dyad, we highlighted the complexities of decision making for dyads with dementia, which clearly extend beyond the question of whether or not a PWD is involved in the process. Other researchers have emphasized the importance of including the PWD and family caregiver together as a dyad in discharge planning during a hospitalization (Bloomer, Digby, Tan, Crawford, & Williams, 2014). This study adds to the literature by providing evidence of extensive variability in PWD involvement in decision making in the acute care setting, and by showing that determinants of perceptions of PWD involvement vary according to whose perspective is solicited (i.e. PWD's or family caregiver's). Future studies should thus continue to include both PWD and family caregiver perspectives while working toward addressing the modifiable aspects of decision-making involvement of PWDs.

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

CHAPTER IV

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

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This manuscript represents a significant contribution to the dissertation work, and replaces aspects of the traditional results and discussion chapters. The target journal for submission is *Aging & Mental Health,* an interdisciplinary journal that covers the biological, psychological and social aspects of aging as they relate to mental health. The journal promotes a strong alliance among the theoretical, experimental and applied sciences across a range of issues affecting mental health and aging. The emphasis of the journal is on rigorous quantitative, and qualitative, research and, high quality innovative studies on emerging topics.

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 limits the family caregiver's ability to make decisions that are in accordance with those values. The objectives of this pilot study were to describe and identify determinants of these incongruent perceptions in the hospital setting.

Methods: Using multilevel modeling, we examined cross-sectional data collected in the inpatient hospital setting from 42 PWD-family caregiver dyads.

Results: There was a significant amount of incongruence, on average, for all 4 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 ($p = .004$). The direction of incongruence was such that 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 for the value of safety/quality of care, and fewer positive dyadic interactions for the value of autonomy.

Conclusion: Our findings show that significant levels of incongruence in perceptions of the PWD's values exist among dementia care dyads in the hospital setting. Exploratory evidence suggests negative consequences of incongruence on the family caregiver's quality of life, and a potential impact of relational variables on incongruence. Further research is needed around this overlooked interpersonal context for supporting the dementia care dyad in the hospital setting.

Keywords: incongruence, dyadic, family caregiving, interpersonal context

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 et al., 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 that 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 et al., 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 et al., 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 et al., 2005b), post-hospital care planning requires additional cognitive abilities including executive function and insight (Sörensen et al., 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 et al., 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 et al., 2006). Without adequate knowledge of PWDs' care values, family caregivers are less likely to use the substituted judgment standard (Hirschman et al., 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 et al., 2007; Heid et al., 2015; Reamy et al., 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 et al., in press; 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, Joyce, James, Xie, & Karlawish, 2005; Moyle et al., 2012; Nelis et al., 2011). Although there is a dearth of knowledge regarding the consequences of such incongruence, one recent study in the community setting indicates that greater PWD-family caregiver incongruence regarding care values is associated with poorer quality of life in PWDs and family caregivers (Moon et al., in press). 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 et al., 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, et al., 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 Outcomes. 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 CG's wellbeing as outcomes (Judge, Menne, et al., 2010; Pearlin et al., 1990). In this study we operationalized the outcome of the stress process of PWD-family caregiver dyads as incongruence regarding the PWD's care values (see Figure 2).

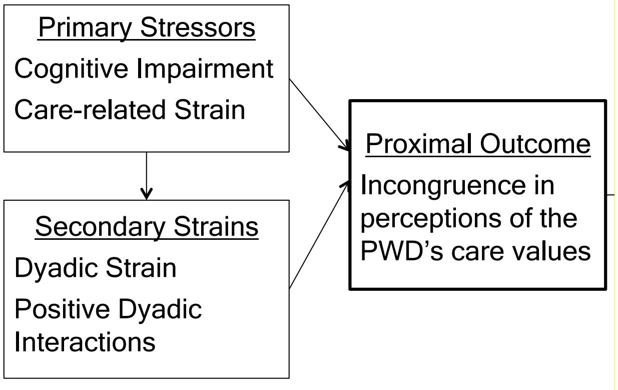

Figure 2. Conceptual model for this study, adapted from versions of the Stress Process Model for family caregivers (Pearlin et al., 1990), and for PWDs (Judge, Menne, et al., 2010).

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, Menne, 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 et al., 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 2). Negative dyadic strain and positive dyadic interactions have previously been conceptualized and applied as secondary strains of the SPM (Judge, Menne, 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

Participants for this study were recruited from adult inpatient acute care units in a university hospital in the Pacific Northwest. Approval was obtained from the Institutional Review Board for this study. A convenience sample of 42 dyads was enrolled that met the following eligibility criteria. **Inclusion criteria**. PWDs were eligible if they were age 65 or older, admitted to an acute care unit, had symptoms consistent with mild to moderate dementia, and self-reported a probable or current diagnosis of an irreversible progressive dementia: Alzheimer's disease, vascular dementia, Lewy body dementia, or frontotemporal dementia. Family caregivers were eligible if they were age 21 or older, 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). To be eligible, PWDs had to score at least 13 (moderate dementia) on the Mini-Mental State Exam, which corresponds to reliable, consistent reporting in previous studies using this criterion (Feinberg & Whitlatch, 2001; Logsdon et al., 2002; Parmelee et al., 1989; Whitlatch et al., 2005b). **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 verbal questions from the researcher. Responses were recorded electronically by the researcher on a laptop using REDCap.

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 α = .51 for PWD, α = .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 α = .57 for PWD, α = .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 α = .62 for PWD, α = .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 α = .50 for PWD, α = .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 et al., 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 et al., 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 et al., 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:

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

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 3). 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; $\beta 1j$) 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 2 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 4): 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 5). 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., in press; 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 2). 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. Our modest sample of fairly homogeneous 42 dyads limited the selection of variables and the generalizability of findings. Additionally, 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. Thus, replication with a larger 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.

CHAPTER V – Summary and Discussion

The movement toward early diagnosis of dementia has effectively lengthened the time that families have together to adjust and plan for future care (Hilgeman et al., 2014; Hirschman et al., 2008; Karlawish et al., 2002; Prince, Bryce, & Ferri, 2011). However, early diagnosis does not infer early care planning. Care planning for PWDs can encompass health-related needs, daily tasks, and social and emotional needs (Sörensen et al., 2011). These issues should ideally be addressed while families can discuss options together. Yet, there is no standard practice or common venue for starting care planning conversations, and the majority of older adults do not plan in advance for care (Hopp, 2000; Sörensen et al., 2011). Consequently, many important decisions are made in haste out of necessity, such as during hospitalization discharge planning (Bloomer et al., 2014; Poole et al., 2014; Swidler et al., 2007). The purpose of this manuscript dissertation was to examine two aspects of dementia care planning within the context of an acute care hospitalization–the PWD's decision-making involvement and care values–from the perceptions of both members of the dementia care dyad. The goal of this body of work was to gain a greater understanding of the influence of the interpersonal context of the dementia care dyad on the PWD's involvement in care planning.

This dissertation work began with the philosophical view, derived from personhood, that including PWDs in care planning validates their sense of agency (i.e. the ability to control their personal life in a meaningful way) (Kitwood & Bredin, 1992). Decision making is an expression of agency, but PWDs inevitably lose decision-making capacity at some point along the dementia trajectory. Yet, there is nothing precluding PWDs from participating in decision making and care planning along with their family members so long as they are able to express a value or preference (Jaworska, 1999), and in doing so we support their personhood (Kitwood & Bredin, 1992).

Although there is a need to examine the extent of PWD involvement in decision making and factors that promote it, especially in the context of the inpatient hospital setting, the solution to the problem of PWDs' involvement is not simply a matter of increasing it. Family caregivers' involvement in decision making is also essential to the decision-making process, since it is necessary to translate the values of PWDs into decisions (Gillick, 2013; Sörensen et al., 2011; Tsou & Karlawish, 2014). Additionally, many PWDs believe that decision making should be a shared responsibility with family members (Adler, 2010; Horton-Deutsch et al., 2007; Karel et al., 2010). The family caregiver's role in care planning is crucial to its formation and implementation, and yet there are a number of stressors and strains upon family caregivers that likely impact the care relationship, and their ability to perform that role.

The Stress Process Model provided the theoretical context in this dissertation for how care planning may be impacted by the stressors and strains that arise from living with or caring for someone with dementia. The first dissertation aim was to examine the decision-making process of dementia care dyads through two manuscripts: a literature review "Shared decision making in dementia: A review of patient and family carer involvement" (Chapter 2), and an empirical study "Involvement of Hospitalized Persons with Dementia in Everyday Decisions: A Dyadic Study" (Chapter 3). The second aim of this dissertation was to describe incongruent perceptions of the care values of hospitalized PWDs, and identify determinants thereof. This aim was met through an empirical manuscript "Incongruent perceptions of the care values of hospitalized persons with dementia: A pilot study of patient-family caregiver dyads" (Chapter 4).

Principle Findings Aim 1: Decision-Making Involvement of PWDs

An extensive review of the literature revealed several findings regarding perspectives of PWD-family caregiver dyads, and the extent and determinants of PWDs' decision-making involvement. Persons with dementia overwhelmingly want to participate in decision-making (Hamann et al., 2011; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Karel et al., 2010; Karel et al., 2007), but family caregivers underestimate PWDs' interest in being involved, or prefer PWDs to be less involved than PWDs prefer (Hamann et al., 2011; Hirschman, Joyce, James, Xie, & Karlawish, 2005). The extent of PWDs' involvement in decision-making is minimal past the mild stage of dementia, which highlights the disconnect between what is possible and what occurs in reality.

The lack of involvement of PWDs in decision making is influenced by a number of factors identified in the literature, only a few of which are modifiable. For the PWD, more cognitive impairment, lack of insight into the disease, older age, and having an adult child (rather than a spouse) as caregiver are all significant predictors of less PWD decision-making involvement (Hirschman, Joyce, James, Xie, Casarett, et al., 2005; Hirschman, Joyce, James, Xie, & Karlawish, 2005; Hirschman et al., 2004; Karlawish et al., 2002; Menne et al., 2008). Modifiable factors related to greater decision-making involvement of PWDs included less care-related strain and fewer depressive symptoms in family caregivers, the value of autonomy held by the PWD, and less relationship strain in the care dyad (Hirschman et al., 2004; Karlawish et al., 2002; Menne et al., 2008; Reamy et al., 2011; Samsi & Manthorpe, 2013; Whitlatch et al., 2009). However, none of these studies were conducted in the inpatient hospital setting.

The empirical study addressing Aim 1 was the first known study (Chapter 3) to examine the everyday decision-making involvement of PWDs in the inpatient hospital setting, which addresses a substantial gap in the literature given that the hospital discharge plan encompasses so many decisions about the dementia care dyad’s daily life. The principle findings of this study were: 1) both members of the dyad rated the PWD on average as being “somewhat involved” in decision making; 2) there was a significant amount of variability around the average perceptions of PWD involvement in decision-making for both PWDs and family caregivers; 3) both PWDs and family caregivers were significantly more likely to perceive greater PWD involvement in decision-making when the family caregiver reported the PWD as valuing autonomy; 4) PWDs were significantly more likely to report greater involvement when they had greater cognitive function; 5) family caregivers perceived significantly greater involvement of the patient in decision-making when they reported less strain in the relationship

Principle Findings Aim 2: Incongruent Perceptions of the PWD’s Care Values

Incongruence in perceptions of the PWD’s care values is problematic because it limits the family caregiver’s ability to make decisions about the care plan that are in accordance with those values. The principle findings of this study were: 1) there was a significant amount of incongruence in perceptions across all four of the PWD’s care values; 2) family caregivers rating the importance for each care value lower than the PWD; 3) factors associated with incongruence included relationship strain and fewer positive interactions in the dyad.

Overall, the results of this dissertation address significant problems in dementia care planning and offer a beginning understanding of the impact of the dementia care relationship on the PWD’s involvement in decision making, and incongruence in perceptions of the PWD’s care values. Several prominent themes related to the results will be discussed, including the use of the Stress Process Model as a guiding framework, autonomy as a running thread throughout the dissertation, the influence of interpersonal context on care planning, and heterogeneity in care planning. The discussion of these themes will be followed by implications of the body of work for the advancement of dementia care planning through theory, research, and practice.

Discussion of Findings

The Stress Process Model

The Stress Process Model provided a framework for examining the barriers to care planning issues highlighted by this dissertation. Two versions of the Stress Process Model, one for the family caregiver and one for the PWD (Judge, Menne, et al., 2010; Pearlin et al., 1990), guided the studies of the PWD's decision-making involvement (Chapter 3) and of PWD-family caregiver incongruence regarding the PWD's care values (Chapter 4). A dyadic version has not previously been conceptualized, yet dementia is a shared context for the PWD and family caregiver. Thus, it was necessary to combine these two versions in order to understand the stress process for both members of the dementia care dyad. The application of the blended versions of the SPM was a novel aspect of this dissertation work.

Blending the two versions of the SPM opens up the possibility to examine the ways in which the two individuals' stress processes interact and affect their relationship. Taken individually, each version of the SPM represents fluctuating components of an ongoing and complex process of the stress that arises from living with or caring for someone with dementia. Pearlin et al. (1990, pg. 591) describe the family caregiver's version as "a mix of circumstances, experiences, responses, and resources that vary considerably among caregivers and that, consequently, vary in their impact." When the family caregiver version is joined with the PWD version (Judge, Menne, et al., 2010), the SPM becomes exponentially more complex. However, it is also a more comprehensive reflection of the reality that an individual's circumstances and experiences include a care relationship.

Stress related to dementia is a dynamic process that manifests within the dyad's relationship as much as it does within the individual's psyche. Results from both of the empirical studies indicated that the care relationship had a significant influence on care planning outcomes, above and beyond the individual-level characteristics (PWD's cognitive impairment and family caregiver's role overload). There were also cross-partner effects in the examination of perceptions of the PWD's decision-making involvement (Chapter 3): the family member's perception of the patient's value of autonomy was a significant factor in both the PWDs' and family caregivers' perceptions of the PWD's decision-making involvement. Thus, the results from this dissertation confirm that a dyadic framework is appropriate and necessary.

Autonomy

Autonomy is a prominent theme throughout this dissertation work. It is clear from the body of research on decision-making capacity that autonomy is not possible for PWDs as dementia progresses (e.g. Arias, 2013; Gurrera et al., 2007; Moye et al., 2006). Autonomous decisions require intact memory, executive function, and insight into one's condition, all of which decline in dementia (Godefroy et al., 2014; Orfei et al., 2010; Tsou & Karlawish, 2014). However, a PWD will still value their autonomy to varying degrees, even if it is not always possible for them to exert it.

The first aim of this dissertation was concerned with the PWD's involvement in decision making, which is one way to support the PWD's autonomy despite increasing dependence upon others during care planning (Tsou & Karlawish, 2014). The early decline in PWDs' decision-making involvement is troublesome given that PWDs want to remain involved in decision making (Hamann et al., 2011; Hirschman, Joyce, James, Xie, & Karlawish, 2005), and are able to reliably communicate their values and preferences through moderate dementia (Karel et al., 2010; Karel et al., 2007; Whitlatch, Feinberg, & Tucke, 2005a).

An important contribution of this body of work has been to examine factors that might help sustain the PWD's involvement in decision making. For many PWDs, there is an extended period between the loss of decisional capacity and the loss of ability to participate in decision-making (Tsou & Karlawish, 2014). Putting findings from the literature review (Chapter 2) together with what is suggested by the empirical findings from Chapter 3, the extent of cognitive impairment clearly has an impact, but it is not the only determinant of the PWD's decision-making involvement. In Chapter 3, greater cognitive function was significantly associated with greater involvement in decision-making, according to PWDs' perceptions. This finding was also apparent in a study conducted in the community setting (Menne & Whitlatch, 2007). However, this study was the first to simultaneously examine factors associated with both PWDs' and family caregivers' perceptions of decision-making involvement, and cognitive function was not a significant factor associated with family caregivers' perceptions. Since MMSE scores were on average in the mild range for this study, a possible explanation is that PWDs begin to question their own capacity, or even withdraw from decision-making, early on in the disease process. In the early stage, when cognitive impairment is less observable, family caregivers' perceptions may be more influenced by factors that are more apparent, such as the changing nature of the care relationship.

Additionally, as was discovered in Aim 1 (Chapter 3), the PWD's value of autonomy (according to family caregiver reports) was a significant factor in the dyads' perceptions of the PWD's decision-making involvement in the acute care setting. This finding is also significant in the community setting, where the PWD's value of autonomy was the only significant secondary strain identified by modeling influences of the stress process on the PWD’s decision-making involvement (Menne & Whitlatch, 2007). The value of autonomy captures how important autonomy is to the PWD, not how much independence remains in the PWD. This difference is critical since dementia continually threatens autonomy, but may not diminish how important autonomy is to a PWD. For example, one PWD participant in this study remarked:

> “I am not afraid to die. I am concerned with a loss of quality of life and not being a whole person. It's seeming unlikely with dementia. My aim of full independence won't be possible and it makes me sad. I am usually a happy person but it is of great concern to me that I won't be able to make my own choices. It's never been out of my control before. I can live with help but not with being dependent on others.”

The patient is acknowledging the loss of capacity due to dementia, which reflects the significant association that was found between cognitive impairment and decision-making involvement. At the same time, this patient is beautifully expressing the paradox between losing autonomy and still valuing it most–much more so than avoiding death it seems. In order to achieve person-centered care, it is necessary to promote the PWD’s contributions and values rather than continually compensate for what the PWD can no longer do (Vernooij-Dassen & Moniz-Cook, 2016). When family caregivers recognize that autonomy is important to the PWD, it may lead to more frequent inclusion of the PWD in decision-making, especially in the acute care setting, where family caregivers are often looked to first and foremost as decision-makers.

Autonomy was also addressed under Aim 2 (Chapter 4) as one of the four care values analyzed in regard to incongruence in PWD-family caregiver dyads. Previous research on care planning in dementia emphasizes the need for early conversations about PWD’s care values and wishes. There was significant incongruence in perceptions of the PWD’s value of autonomy, with family caregivers underestimating how important autonomy is to the PWD. These results reflect that early conversations may not be happening frequently enough for PWDs to be able to express what is important to them. Additionally, there are reasons why early conversations may not be very effective. Family caregiver's reports of care values are colored by negative appraisals related to the stress process. No matter how many times a dyad discusses the PWD's value of autonomy, it is possible that family caregivers' perceptions of the dyad's relationship lead them to have more difficulty hearing the importance of it to the PWD. For example, in Aim 2, the family caregiver's perception of fewer positive interactions in the care relationship was significantly associated with greater incongruence regarding the value of autonomy. The lack of closeness, or fewer gains from the care relationship, could cloud the family caregiver's perceptions of the PWD's value of autonomy.

The Dementia Care Dyad and the Interpersonal Context

There were several reasons for including both members of the dyad in this dissertation. The most important rationale for including PWDs is because we know that they are able to express their values and preferences. Participants in this study all self-reported a diagnosis of a primary progressive dementia, and had Mini-mental State Exam scores in the range of 12 to 27 (mean = 20.55 ±3.86), which generally corresponds with mild to moderate dementia. All participants were able to complete the Care Values Scale without difficulty or missing data. We also know that family caregivers are not very accurate as surrogate decision-makers (Shalowitz et al., 2006), so we cannot necessarily rely upon family caregivers to make decisions that reflect the PWD's values without gaining the PWD's input. This rationale was reinforced by the finding of significant incongruence in perceptions of the PWD's care values (Chapter 4). Finally, the PWD is the patient. In the era of person-centered care, this should not be overlooked.

Likewise, there are several reasons to include family caregivers in care planning. We need family caregivers on board during care planning due to the likelihood of impaired executive function and lack of insight into care needs among PWDs. With these impairments it is simply difficult for PWDs to connect their values to the decisions at hand. Several family caregiver participants substantiated this rationale in the final question of the study survey, which asked if there was anything else that they would like to share. For example, one family member responded:

> “She's stubborn and doesn't realize she can't do everything herself. I have to talk with her and give her options without forcing her into decisions. I don't want her to be unhappy but she can't make choices alone anymore. She has to see that there are alternatives otherwise she sticks to an unrealistic plan.”

The family caregiver is inevitably responsible for implementing a great deal of the care plan, and it is necessary to know whether or not the care plan is realistic for them. However, including both the PWD and family caregiver in care planning is a more complex goal.

In general, dementia has a negative impact on the quality of the relationship between family members (Aneshensel et al., 1995). However, the extent of this impact is highly variable, and many family caregivers simultaneously experience gains from entering into a care relationship (Gaugler, Kane, & Langlois, 2000; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). In this study, family caregivers’ perceptions of their relationship with the PWD reflected both a moderate level of strain and a high level of positive interactions, on average, and the two perceptions were not correlated. Positive dyadic interactions encompass transactions of closeness and positive regard for oneself and others that come as a result of being in the care relationship; relationship strain represents anger, resentment, and other strains upon the relationship in the context of providing care (Sebern & Whitlatch, 2007). A lack of positive interactions does not necessarily imply a strained relationship. For example, a spouse caregiver whose premorbid feelings were of extreme closeness with her husband could diminish as dementia progresses and the care duties take over, but she may not feel any resentment or anger about the changing nature of the relationship.

The complexity of the care dyad's relationship is most likely magnified by the acute care setting. A hospitalization usually occurs as a result of an acute illness that is unrelated to dementia. Worry over the PWD's health status and concern for the family caregiver's ability to continue providing care are of primary concern for dementia care dyads (Bloomer et al., 2014). Evidence suggests that a hospitalization can exacerbate tensions in the care relationship, or become a time of loneliness, especially for spouse caregivers (Crawford, Digby, Bloomer, Tan, & Williams, 2015; Dewing & Dijk, 2016). Overall, it is clear that a hospitalization can be a time of great vulnerability for both the PWD and family caregiver. Results from both Aims 1 & 2 indicate that the care relationship is a significant factor associated with the PWD's involvement in decision making, and a significant factor associated with the extent of incongruence in perceptions of care values. Thus, this study suggests that positive and negative aspects of the dementia care dyad's relationship likely influence dementia care planning.

Multilevel Modeling and Heterogeneity

The primary analytic technique used in these studies was multilevel modeling, which was advantageous for handling dyadic data (see Chapters 3 & 4 for descriptions of advantages). Multilevel modeling allowed for an examination of the differences between perceptions in the dementia care dyad regarding care planning issues. The results of Aim 2 (Chapter 4) are consistent with findings from studies in the community setting indicating significant incongruence in PWD-family caregiver perceptions of PWD's care values. Another type of difference highlighted by multilevel modeling in Aim 1 (Chapter 3) was that the perceptions of PWDs and family caregivers regarding the PWD’s decision-making involvement are influenced by different factors (e.g. cognitive impairment for the PWD and relationship strain for the family caregiver). Although there were similar differences identified in studies conducted in the community setting (reviewed in Chapter 2), this study was the first study to simultaneously examine factors associated with dyad members’ perceptions (i.e. differences in perceptions were identified across studies in the literature review). These differences in determinants of perceptions reflect the distinct challenges and needs of PWDs and family caregivers (e.g. cognitive impairment versus strain in the relationship). Overall, findings from this dissertation underscore the imperative to involve both PWDs and family caregivers in research efforts to improve the PWD’s involvement in care planning, and to use methods appropriate for studying the complexity of dyads.

Multilevel modeling also facilitated the examination of variability across dyads’ perceptions. In five out of the six multilevel outcomes included in this dissertation (Aim 1 resulted in two perceptions of decision-making involvement; Aim 2 included four separate analyses for the four care values), there was significant variability around the average scores. Prior to this study, methods appropriate for analyzing variability in the decision making of PWD-CG dyads had yet to be employed, even in cross-sectional data. That is, only average levels of PWD involvement in decision-making have been studied. This study was the first to use multilevel modeling to examine PWD-family caregiver perceptions of the PWD’s decision-making involvement (Chapter 3). In Chapter 4, the variability around average levels of incongruence in perceptions of care values was found to be significant, which is consistent with a previous study using multilevel modeling to examine incongruent perceptions of care values among community-dwelling dyads (Reamy et al., 2011). The conclusion we can draw from these findings is that there were many dyads for whom the average was not an accurate representation. In other words, there was extensive heterogeneity in the perceptions of care planning issues across dementia care dyads in this study, which warrants future research.

Implications

Theoretical Implications

Dementia fundamentally alters the way in which the two members of the care dyad interact and view their relationship. The process of dementia-related stressors and strains affecting the wellbeing of PWDs and family caregivers has been explained previously in separate individual versions of the Stress Process Model (Judge, Menne, et al., 2010; Pearlin et al., 1990). The results of this dissertation highlight the importance of the care relationship, which is best examined through a framework that captures the interactive nature of the dementia care dyad. There is clearly a need for a dyadic version of the SPM, which should be attended to in future theoretical work.

Another theoretical implication concerns testing the directionality of relationships between components of the Stress Process Model. As an example, one tension inherent in using the SPM for examining decision-making involvement in the PWD is the conceptualization of depression as an outcome. In both versions of the SPM, depression is conceptualized as an outcome since it is related to wellbeing, which is continually threatened by the stress of living with dementia (Judge, Menne, et al., 2010; Pearlin et al., 1990). Thus, depressive symptoms were not included as a covariate in any of the analyses for this dissertation work. However, in clinical practice, it is recognized that depression can impair decision-making capacity, and thus may influence perceptions of the PWD’s involvement in decision making (Tsou & Karlawish, 2014).

In order to reconcile this tension, the SPM would need to be tested for directionality of relationships between variables using a method such as structural equation modeling, which could address the likelihood of a recursive relationship between outcomes such as depression and decision-making involvement of PWDs.

Finally, in this dissertation work, the secondary strains were more influential than the primary stressors upon outcomes in the SPM (see Figure 2., page 6). These included the importance of autonomy to the PWD (from the perspective of the family caregiver), and aspects of the dementia care dyad's relationship (dyadic strain and positive dyadic interactions). Importantly, these variables are modifiable, whereas many of the primary stressors in the SPM, such as the extent of cognitive impairment, are not modifiable. The concept of stress proliferation, which has previously been described in relation to the SPM, explains that secondary strains are more variable manifestations of the primary dementia-related stressors, and they can rapidly proliferate depending on the individuals' circumstances (Aneshensel et al., 1995). Fortunately, since the secondary strains are modifiable, the stress process for dementia care dyads may be amenable to interventions that could improve the decision-making process and incongruence regarding the PWD's care values.

Directions for Future Research

The importance of autonomy. PWDs are in a vulnerable position during decision-making due to decreasing capacity, especially in the inpatient hospital setting where they can be excluded entirely from discharge planning (Greener et al., 2012). In this study, PWDs and family caregivers both perceived that the PWD's decision-making involvement was greater when the family caregiver reported that the PWD valued their autonomy highly. One implication of this finding is that when family caregivers recognize the importance of autonomy to PWDs, they may be effectively helping PWDs live up to that value by involving them in decision making. Yet, it is also apparent from this dissertation study as well as research conducted in the community setting that family caregivers underestimate the importance of autonomy to PWDs (Reamy et al., 2011). One mechanism through which family caregivers could help improve PWDs' involvement in decision making would thus be their knowledge of PWDs' value of autonomy. However, all research on the relationships between these variables to date has been cross-sectional, and so it is equally likely that higher decision-making involvement is the beginning point from which PWDs demonstrate their autonomy and reinforce family caregivers' perceptions of the importance of autonomy to the PWD. Additionally, a family caregiver who is supportive of the PWD's involvement in decision-making may also be more adept at deciphering the values of the PWD (Reamy et al., 2011). Future longitudinal research is clearly needed with a larger sample in order to establish the direction of the relationship between the family caregiver's knowledge of values (i.e. incongruent perceptions) and decision-making involvement of PWDs.

There are also implications for the autonomy of PWDs in the connection between the findings of significant incongruence (Aim 2) and the family caregiver's involvement as a surrogate decision maker. Family caregivers are often called upon as surrogate decision makers later in dementia, but also in the inpatient hospital setting at even mild levels of cognitive impairment (Emmett et al., 2013; Swidler et al., 2007). However, surrogate decision makers are not very accurate at predicting patients' wishes, especially when the patient has dementia (Shalowitz et al., 2006). Additionally, the family caregiver's ability to make surrogate decisions in line with the PWD's values is challenged by the substantial pressure and time constraints of the acute care setting (Nilsson et al., 2013). Incongruent perceptions regarding the PWD's care values imply that family caregivers will not be able to carry out the substituted judgment standard as surrogate decision makers. Future research connecting these two concepts would be an important next step to improving the autonomy of PWDs.

Many obstacles exist, even among cognitively intact dyads, to implementing programs that have the potential to support the patient's autonomy and improve shared decision making (Wolff, Roter, Given, & Gitlin, 2009). The complexity of care, competing needs of PWD and family caregiver, and uncertainty surrounding the PWD's cognitive abilities are all examples of obstacles that could hinder the dyad's progress toward these goals. However, it may still be feasible to at the very least educate families about the importance of autonomy to PWDs, and the capabilities of PWDs to voice their values and preferences in the face of memory decline. One dyadic skills training intervention, for example, has shown promise for improving knowledge related to care planning and coping with dementia-related stress (Judge, Yarry, & Orsulic-Jeras, 2010). It is clear from this dissertation and previous research that there are a wide range of types of dementia care dyads, and future research will need to take this variability into account. Some dyads who have greater capacity to participate in interventions together could experience additional benefits from counseling sessions to improve the dyad's communication around values and preferences (Van't Leven et al., 2013; Whitlatch et al., 2006) or from support groups that target family communication more broadly (Logsdon et al., 2010) as a strategy to improve the dementia care dyad's relationship.

Heterogeneity across dyads. The current dissertation study identified significant variability across dyads' perceptions of care planning issues, which calls for further research examining the heterogeneity of decision-making and incongruence. One possible line of inquiry that could stem from these findings is a subgroup analysis of care planning issues across dyads. For example, typologies of dyads could emerge around distinct combinations of PWDs and family caregivers, such as highly incongruent dyads with family caregivers underestimating PWDs' care values, the opposite, or gradients in between. Profiles of decision-making involvement of PWDs and patterns of incongruence in dyads could be identified using the large sample approach of latent class mixture modeling, which would determine if typologies of care planning exist among PWD-family caregiver dyads. A similar analytic approach has been used among heart failure care dyads using cross-sectional data to identify typologies of self-management behaviors (Lee et al., 2015). If typologies of care planning exist among dementia care dyads, predictors could then be examined in order to identify potential targets for interventions tailored to the distinct subgroups.

The complexity and variability around decision-making and incongruence regarding care values has yet to be fully illuminated in longitudinal research, which is necessary in order to understand what predicts these outcomes. As detailed in Chapter 2, both PWDs' and CGs' perceptions need to be included and studied across time to determine the role of individual and dyadic perceptions of decision making as dementia progresses. Only one study could be identified that examined decision making in PWD-CG dyads over time, but that study measured the CG's perception of the PWD's decision-making involvement rather than the dyad's (Hirschman et al., 2004). Additionally, there have been no longitudinal studies on incongruent perceptions of the PWD's care values. One approach to achieving this understanding of dyads' care planning over time is longitudinal multilevel modeling (Lyons & Sayer, 2005a). This technique would help tease out the complexity of individual versus dyadic aspects of care planning over time, and establish directionality between theoretically proposed predictor variables and distal outcomes.

Another promising aim for future longitudinal research would be to determine there is more than one distinct trajectory of change in dyads' decision-making and incongruence in perceptions of care values over the course of dementia (or over the course of transitions from community to hospital and/or long-term care settings). Growth mixture modeling would be an ideal approach to accomplish this aim with a large sample of dyads. It is possible that the significant variability around the average perceptions of decision-making involvement and care values could be due to several distinct patterns of care planning among dementia care dyads, and this approach would address such a hypothesis.

Dyadic care planning interventions. A major hindrance to the involvement of PWDs in care planning is the lack of discussions during early-stage dementia, leading to the failure of PWD-CG dyads to explore options together while all the options are still available (Adler, 2010; Horton-Deutsch et al., 2007; St-Amant et al., 2012; Wolfs et al., 2012). Findings from Aim 2 regarding the significant amount of incongruence in perceptions of the PWD's care values implies that interventions are needed to improve communication and care planning in the early-stage of dementia. Yet, few interventions of this sort exist, especially those that include both the PWD and CG. Even interventions to help family caregivers plan for future dementia care (without PWD participation) are lacking (Ducharme et al., 2011). In Aim 1 of this dissertation (Chapter 2), only four interventions aimed specifically at improving the decision-making process of dementia care dyads could be identified (Hilgeman et al., 2014; Murphy & Oliver, 2013; Silverstein & Sherman, 2010; Whitlatch et al., 2006). Another recent review of early-stage dyadic interventions for PWDs and CGs (Moon & Adams, 2013), identified two additional interventions that addressed other aspects of care planning (Roberts & Silverio, 2009; Zarit et al., 2004).

Although the above-mentioned dyadic interventions demonstrated the feasibility of including the PWD in dyadic interventions, the goals of the interventions, especially for PWDs, have been limited. Future dyadic interventions are needed to promote the PWD's involvement in care planning. The results of this dissertation and other previous research suggest that one way to accomplish this goal may be through enhancing the dyad's relationship. Another potential area for care planning interventions to address is incongruence regarding care values, which this dissertation and other studies have shown to be high among dementia care dyads. Decreasing incongruence may also have the added benefit of enhancing quality of life in dyads, although evidence to support this is preliminary (Moon et al., in press). Tentatively, specific suggestions for intervention targets include building knowledge in the dyad of common care planning issues and the PWD's values for care, mitigating strain in the dyad's relationship so that family caregivers can be more receptive to the PWD's involvement and values for care, and facilitating opportunities for engaging in positive interactions in the dyad in order to maintain the closeness and positive regard for the care relationship. However, it is very likely that interventions using these strategies would need to begin early and be sustained for longer than the length of a hospital admission in order to improve the dyad's relationship and care planning generally.

Ideally, future interventions would also use a tailored approach to address the divergent needs of PWDs and family caregivers, and to target distinct subgroups of dyads that emerge from the heterogeneity analysis described in the previous section. An approach such as latent class mixture modeling could be used in future research with larger samples to examine subgroups of dyads who respond differently to care planning interventions, and allow for the prediction of differential response (i.e. "responders" versus "non-responders"). Sample size has been a major challenge to dyadic interventions (Judge, Yarry, et al., 2010; Murphy & Oliver, 2013), and one of the most critical limitations to overcome in order to have enough power to determine differential responses, and predictors of which dyads respond most favorably. Yet even in the largest identified dyadic intervention study (n = 142 dyads) for early-stage dementia, predicting differential response by post-hoc chi-square and ANOVA techniques that pool PWDs and CGs into the same groups and do not account for the interrelatedness of dyad members, nor do they account for multiple comparisons (Logsdon et al., 2010).

In other previous dyadic interventions, outcomes for PWDs and family caregivers have been analyzed in separate models, which limits what can be concluded about the effect on the dyad, and also does not account for the fact that there is shared variance between individuals in the dyad (Sayer & Klute, 2005). In the future, differences between PWD and family caregiver responses to dyadic interventions should be approached with a technique such as multilevel modeling, which allows outcomes for the two individuals to be assessed simultaneously and at the level of the dyad (Lyons & Sayer, 2005b). This more comprehensive approach would also yield information about whether there are consequences for individual members (e.g. care-related strain increases) when the dyad's outcome (e.g. incongruence) improves, or conversely whether individual members may benefit from aspects of dyadic interventions despite the lack of success for the dyad (Lyons & Sayer, 2005b).

Finally, future care panning interventions will need to address the tension around the potential for improving the care planning process for one dyad member at the expense of the other. For example, does an intervention to improve the PWD's involvement in decision making have the unintended consequence of increasing caregiver strain? Using appropriate dyadic methods and an intervention design that includes outcomes for both dyad members (described above), the relative merits of interventions for the dyad and for individual members of the dyad need to be examined. There may be some situations in which a dyadic care planning intervention is simply not appropriate or useful, such as during the process of a family member disengaging from their caregiving role, or ending their caregiving "career" (Aneshensel et al., 1995). Yet, these situations are usually brief and distinct from the rest of the course of the dementia care dyad's experience (St-Amant et al., 2012). The ultimate goal is to strike a balance in the dyad that allows individual members to experience gains in the care planning process without significant detriment to either dyad member's health or quality of life.

Implications for Clinical Practice

The findings from this dissertation offer beginning guidance for improvements to care planning. Previous literature and empirical findings from Aim 1 all point toward the importance of early care planning, since memory and other impairments related to dementia continuously assault the PWD's involvement in decision-making. There is quite simply a limit to the improvements that can be made upon the PWD's involvement past a certain point of impairment. Fortunately, diagnostic capabilities are constantly improving, and for many families who seek a diagnosis this means that there will be years, if not a decade or longer, during which a PWD can contribute to care planning discussions and specific decisions regarding their care. Early diagnosis affords PWDs time to discuss care plans with their family members and providers, but the task for future research is to discover ways to improve this process.

At this juncture, recommendations for improving clinical practice are thus still premature. However, tentative suggestions based upon this beginning examination of care planning in the acute care setting are: 1) assess and document cognitive impairment and the patient's interest in participating in care planning as a fundamental strategy to alert care management to patients that may need additional support in discharge planning; 2) include both the patient and family member in discharge planning when possible; 3) facilitate conversations about care values between the PWD and family caregiver in order to help family caregivers gain knowledge of the PWD's care values; 4) emphasize the importance of maintaining the care dyad's relationship.

Conclusion

When dementia is diagnosed in the early stage, the years that follow can represent a kind of purgatory for families between the life they knew and the life that will ultimately be taken by the disease. During that precious time, it is possible for a PWD to lead a full life by expressing their values and maintain close relationships with their family members. However, one of the most disturbing aspects of dementia is the gradual erosion of a person's identity: robbing the PWD of skills, memories, and trust in themselves as an independent being. The result is often dependency upon a family member to help determine the best plan for the precious years that remain.

The inpatient hospital setting is one place in which many decisions are made, and where most PWDs will find themselves at some point during the dementia trajectory. It is also a unique opportunity to assist patients with dementia and their family members to plan together for care while there are multiple resources, specialists, and other providers on hand. This dissertation work offers a beginning step toward improving the care planning process for PWDs and their family caregivers in the inpatient hospital setting and beyond. The extent of cognitive impairment will be a limiting factor for PWDs' involvement. Yet, finding ways for the family caregiver to recognize the importance of autonomy to the PWD, and supporting the care relationship between the PWD and family caregiver, are promising targets for future research aimed at understanding and intervening in the care planning process of dementia care dyads. Looking toward the future, the ultimate goals of this line of research will be to 1) assist PWDs in participating in their own care planning to the fullest extent possible; 2) assist family caregivers in their transition to surrogate decision-making, and, most importantly, 3) support the dementia care dyad as a unit so that they are able to find a new balance between their relationship and their individual needs as they plan together for future care.

References

Adler, G. (2010). Driving decision-making in older adults with dementia. *Dementia, 9*(1), 45-60. doi:10.1177/1471301209350289

Algase, D. L., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease and other Dementias, 11*(6), 10-19.

Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego, CA: Academic Press.

Arias, J. J. (2013). A time to step in: legal mechanisms for protecting those with declining capacity. *American Journal of Law & Medicine, 39*(1), 134-159.

Association, A. s. (2014). 2014 Alzheimer's Disease Facts and Figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association, 10*(2), e47-e92. doi:10.1016/j.jalz.2014.02.001

Ayalon, L., Bachner, Y. G., Dwolatzky, T., & Heinik, J. (2012). Preferences for end-of-life treatment: concordance between older adults with dementia or mild cognitive impairment and their spouses. *Int Psychogeriatr, 24*(11), 1798-1804. doi:10.1017/S1041610212000877

Bartlett, R., & O'Connor, D. (2007). From personhood to citizenship: Broadening the lens for dementia practice and research. *Journal of Aging Studies, 21*(2), 107-118. doi:10.1016/j.jaging.2006.09.002

Beauchamp, T. L., & Childress, J. F. (2009). *Principles of Biomedical Ethics* (6 ed.): Oxford University Press.

Black, B. S., Fogarty, L. A., Phillips, H., Finucane, T., Loreck, D. J., Baker, A., . . . Rabins, P. V. (2009). Surrogate decision makers' understanding of dementia patients' prior wishes for end-of-life care. *J Aging Health, 21*(4), 627-650. doi:10.1177/0898264309333316

Bloomer, M., Digby, R., Tan, H., Crawford, K., & Williams, A. (2014). The experience of family carers of people with dementia who are hospitalised. *Dementia (London)*. doi:10.1177/1471301214558308

Borson, S., Frank, L., Bayley, P. J., Boustani, M., Dean, M., Lin, P. J., . . . Ashford, J. W. (2013). Improving dementia care: the role of screening and detection of cognitive impairment. *Alzheimers Dement, 9*(2), 151-159. doi:10.1016/j.jalz.2012.08.008

Boyer, F., Novella, J. L., Morrone, I., Jolly, D., & Blanchard, F. (2004). Agreement between dementia patient report and proxy reports using the Nottingham Health Profile. *Int J Geriatr Psychiatry, 19*(11), 1026-1034. doi:10.1002/gps.1191

Boyle, G. (2008). The Mental Capacity Act 2005: Promoting the citizenship of people with dementia? . *Health and Social Care in the Community, 16*(5), 529-537. doi:10.1111/j.1365-2524.2007.00775.x

Boyle, G. (2013). 'She's usually quicker than the calculator': financial management and decision-making in couples living with dementia. *Health Soc Care Community, 21*(5), 554-562. doi:10.1111/hsc.12044

Braun, M., Scholz, U., Bailey, B., Perren, S., Hornung, R., & Martin, M. (2009). Dementia caregiving in spousal relationships: a dyadic perspective. *Aging Ment Health, 13*(3), 426-436. doi:10.1080/13607860902879441

Brooker, D. (2007). *Person-Centered Dementia Care: Making Services Better*. London: Jessica Kingsley Pub.

Buckley, T., Fauth, E. B., Morrison, A., Tschanz, J., Rabins, P. V., Piercy, K. W., . . . Lyketsos, C. G. (2012). Predictors of quality of life ratings for persons with dementia simultaneously reported by patients and their caregivers: the Cache County (Utah) Study. *Int Psychogeriatr, 24*(7), 1094-1102. doi:10.1017/S1041610212000063

Buron, B. (2008). Levels of personhood: a model for dementia care. *Geriatr Nurs, 29*(5), 324-332. doi:10.1016/j.gerinurse.2007.11.001

Butcher, H. K., Holkup, P. A., Park, M., & Maas, M. L. (2001). Thematic analysis of the experience of making a decision to place a family member with Alzheimer's disease in a special care unit. *Res Nurs Health, 24*, 470-480.

Caldwell, L., Low, L. F., & Brodaty, H. (2014). Caregivers' experience of the decision-making process for placing a person with dementia into a nursing home: comparing caregivers from Chinese ethnic minority with those from English-speaking backgrounds. *Int Psychogeriatr, 26*(3), 413-424. doi:10.1017/S1041610213002020

Callahan, C. M., Arling, G., Tu, W., Rosenman, M. B., Counsell, S. R., Stump, T. E., & Hendrie, H. C. (2012). Transitions in care for older adults with and without dementia. *J Am Geriatr Soc, 60*(5), 813-820. doi:10.1111/j.1532-5415.2012.03905.x

Cano, A., Johansen, A. B., & Franz, A. (2005). Multilevel analysis of couple congruence on pain, interference, and disability. *Pain, 118*(3), 369-379. doi:10.1016/j.pain.2005.09.003

Caplan, G. A., Meller, A., Squires, B., Chan, S., & Willett, W. (2006). Advance care planning and hospital in the nursing home. *Age Ageing, 35*(6), 581-585. doi:10.1093/ageing/afl063

Caron, C. D., Ducharme, F., & Griffith, J. (2006). Deciding on institutionalization for a relative with dementia: the most difficult decision for caregivers. *Canadian Journal on Aging, 25*(2), 193-205.

Carpenter, B. D., Kissel, E. C., & Lee, M. M. (2007). Preferences and life evaluations of older adults with and without dementia: reliability, stability, and proxy knowledge. *Psychol Aging, 22*(3), 650-655. doi:10.1037/0882-7974.22.3.650

Chang, Y. P., & Schneider, J. K. (2010). Decision-making process of nursing home placement among Chinese family caregivers. *Perspect Psychiatr Care, 46*(2), 108-118. doi:10.1111/j.1744-6163.2010.00246.x

Chenoweth, L., King, M. T., Jeon, Y. H., Brodaty, H., Stein-Parbury, J., Norman, R., . . . Luscombe, G. (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet Neurology, 8*(4), 317-325.

Conde-Sala, J. L., Garre-Olmo, J., Turro-Garriga, O., Lopez-Pousa, S., & Vilalta-Franch, J. (2009). Factors related to perceived quality of life in patients with Alzheimer's disease: the patient's perception compared with that of caregivers. *Int J Geriatr Psychiatry, 24*(6), 585-594. doi:10.1002/gps.2161

Cotrell, V., & Schulz, R. (1993). The perspective of the patient with Alzheimer's disease: A neglected dimension of dementia research. *Gerontologist, 33*(2), 205-211.

Couture, M., Ducharme, F., & Lamontagne, J. (2012). The Role of Health care Professionals in the Decision-Making Process of Family Caregivers Regarding Placement of a Cognitively Impaired Elderly Relative. *Home Health Care Management & Practice, 24*(6), 283-291. doi:10.1177/1084822312442675

Crawford, K., Digby, R., Bloomer, M., Tan, H., & Williams, A. (2015). Transitioning from caregiver to visitor in a long-term care facility: the experience of caregivers of people with dementia. *Aging Ment Health, 19*(8), 739-746. doi:10.1080/13607863.2014.962008 de Boer, M. E., Dröes, R.-M., Jonker, C., Eefsting, J. A., & Hertogh, C. M. P. M. (2012). Thoughts on the Future: The Perspectives of Elderly People with Early-Stage Alzheimer's Disease and the Implications for Advance Care Planning. *AJOB Primary Research, 3*(1), 14-22. doi:10.1080/21507716.2011.636784

Dening, K. H., Jones, L., & Sampson, E. L. (2013). Preferences for end-of-life care: a nominal group study of people with dementia and their family carers. *Palliat Med, 27*(5), 409-417. doi:10.1177/0269216312464094

Dewing, J., & Dijk, S. (2016). What is the current state of care for older people with dementia in general hospitals? A literature review. *Dementia (London), 15*(1), 106-124. doi:10.1177/1471301213520172

Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society, 17*, 597-607.

Dresser, R. (2001). Advance directives in dementia research: promoting autonomy and protecting subjects. *IRB, 23*(1), 1-6.

Dresser, R. S. (1992). Autonomy Revisited: The Limits of Anticipatory Choices. In R. H. Binstock, S. G. Post, & P. J. Whitehouse (Eds.), *Dementia and Aging: Ethics, Values, and Policy Choices*. Baltimore: The Johns Hopkins University Press.

Ducharme, F. C., Levesque, L. L., Lachance, L. M., Kergoat, M. J., Legault, A. J., Beaudet, L. M., & Zarit, S. H. (2011). "Learning to become a family caregiver" efficacy of an intervention program for caregivers following diagnosis of dementia in a relative. *Gerontologist, 51*(4), 484-494. doi:10.1093/geront/gnr014

Dworkin, R. (1993). *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*. New York: Alfred A. Knopf.

Edvardsson, D., Nilsson, A., Fetherstonhaugh, D., Nay, R., & Crowe, S. (2013). The person-centred care of older people with cognitive impairment in acute care scale (POPAC). *J Nurs Manag, 21*(1), 79-86. doi:10.1111/j.1365-2834.2012.01422.x

Edvardsson, D., & Nordvall, K. (2008). Lost in the present but confident of the past: experiences of being in a psycho-geriatric unit as narrated by persons with dementia. *J Clin Nurs, 17*, 491-498.

Edvardsson, D., Sandman, P. O., & Borell, L. (2014). Implementing national guidelines for person-centered care of people with dementia in residential aged care: effects on perceived person-centeredness, staff strain, and stress of conscience. *Int Psychogeriatr*, 1-9. doi:10.1017/S1041610214000258

Edvardsson, D., Winblad, B., & Sandman, P. O. (2008). Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *The Lancet Neurology, 7*(4), 362-367. doi:10.1016/s1474-4422(08)70063-2

Elliott, B. A., Gessert, C. E., & Peden-McAlpine, C. (2007). Decision making on behalf of elders with advanced cognitive impairment: family transitions. *Alzheimer Dis Assoc Disord, 21*(1), 49-54. doi:10.1097/WAD.0b013e318030840a

Elliott, B. A., Gessert, C. E., & Peden-McAlpine, C. (2009). Family decision-making in advanced dementia: narrative and ethics. *Scand J Caring Sci, 23*(2), 251-258. doi:10.1111/j.1471-6712.2008.00613.x

Emmett, C., Poole, M., Bond, J., & Hughes, J. C. (2013). Homeward bound or bound for a home? Assessing the capacity of dementia patients to make decisions about hospital discharge: comparing practice with legal standards. *Int J Law Psychiatry, 36*(1), 73-82. doi:10.1016/j.ijlp.2012.11.009

Epstein-Lubow, G., Gaudiano, B., Darling, E., Hinckley, M., Tremont, G., Kohn, R., . . . Miller, I. W. (2012). Differences in depression severity in family caregivers of hospitalized individuals with dementia and family caregivers of outpatients with dementia. *Am J Geriatr Psychiatry, 20*(9), 815-819. doi:10.1097/JGP.0b013e318235b62f

Ericson, I., Hellström, I., Lundh, U., & Nolan, M. (2001). What constitutes good care of people with dementia? *British Journal of Nursing, 10*(11), 710-714.

Feinberg, L. F., & Whitlatch, C. J. (2001). Are persons with cognitive impairment able to state consistent choices? *Gerontologist, 41*(3), 374-382.

Feinberg, L. F., & Whitlatch, C. J. (2002). Decision-making for persons with cognitive impairment and their family caregivers. *American Journal of Alzheimer's Disease and other Dementias, 17*(4), 237-244. doi:10.1177/153331750201700406

Fetherstonhaugh, D., Tarzia, L., & Nay, R. (2013). Being central to decision making means I am still here!: the essence of decision making for people with dementia. *J Aging Stud, 27*(2), 143-150. doi:10.1016/j.jaging.2012.12.007

Fillenbaum, G. G., Heyman, A., Wilkinson, W. E., & Haynes, C. S. (1987). Comparison of two screening tests in Alzheimer's disease. The correlation and reliability of the Mini-Mental State Examination and the modified Blessed test. *Arch Neurol, 44*(9), 924-927.

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. *J Psychiatr Res, 12*(3), 189-198.

Fortinsky, R. H., & Downs, M. (2014). Optimizing person-centered transitions in the dementia journey: a comparison of national dementia strategies. *Health Aff (Millwood), 33*(4), 566-573. doi:10.1377/hlthaff.2013.1304

Gaugler, J. E., Kane, R. A., & Langlois, J. (2000). Assessment of family caregivers of older adults. In R. L. Kane & R. A. Kane (Eds.), *Assessing Older Persons: Measures, Meaning, and Practical Applications* (pp. 320-359). New York: Oxford University Press.

Gillick, M. R. (2013). The critical role of caregivers in achieving patient-centered care. *JAMA, 310*(6), 575-576. doi:10.1001/jama.2013.7310

Godefroy, O., Martinaud, O., Verny, M., Mosca, C., Lenoir, H., Bretault, E., & Roussel, M. (2014). The dysexecutive syndrome of Alzheimer's disease: The GREFEX study. *Journal of Alzheimer's Disease, 42*(4), 1203-1208. doi:10.3233/JAD-140585

Goodman, C., Amador, S., Elmore, N., Machen, I., & Mathie, E. (2013). Preferences and priorities for ongoing and end-of-life care: a qualitative study of older people with dementia resident in care homes. *Int J Nurs Stud, 50*(12), 1639-1647. doi:10.1016/j.ijnurstu.2013.06.008

Greener, H., Poole, M., Emmett, C., Bond, J., Louw, S. J., & Hughes, J. C. (2012). Value judgements and conceptual tensions: decision-making in relation to hospital discharge for people with dementia. *Clinical Ethics, 7*(4), 166-174. doi:10.1258/ce.2012.012028

Gurrera, R. J., Karel, M. J., Azar, A. R., & Moye, J. (2007). Agreement between instruments for rating treatment decisional capacity. *American Journal of Geriatric Psychiatry, 15*(2), 168-173.

Hamann, J., Bronner, K., Margull, J., Mendel, R., Diehl-Schmid, J., Buhner, M., . . . Perneczky, R. (2011). Patient participation in medical and social decisions in Alzheimer's disease. *J Am Geriatr Soc, 59*(11), 2045-2052. doi:10.1111/j.1532-5415.2011.03661.x

Heid, A. R., Bangerter, L. R., Abbott, K. M., & Van Haitsma, K. (2015). Do Family Proxies Get It Right? Concordance in Reports of Nursing Home Residents' Everyday Preferences. *J Appl Gerontol*. doi:10.1177/0733464815581485

Hilgeman, M. M., Allen, R. S., Snow, A. L., Durkin, D. W., DeCoster, J., & Burgio, L. D. (2014). Preserving Identity and Planning for Advance Care (PIPAC): preliminary outcomes from a patient-centered intervention for individuals with mild dementia. *Aging Ment Health, 18*(4), 411-424. doi:10.1080/13607863.2013.868403

Hirschman, K. B., Joyce, C. M., James, B. D., Xie, S. X., Casarett, D. J., & Karlawish, J. (2005). Would caregivers of Alzheimer disease patients involve their relative in a decision to use an AD-slowing medication? *Am J Geriatr Psychiatry, 13*(11), 1014-1021. doi:10.1176/appi.ajgp.13.11.1014

Hirschman, K. B., Joyce, C. M., James, B. D., Xie, S. X., & Karlawish, J. (2005). Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *Gerontologist, 45*(3), 381-388.

Hirschman, K. B., Kapo, J. M., & Karlawish, J. (2006). Why doesn't a family member of a person with advanced dementia use a substituted judgment when making a decision for that person? *American Journal of Geriatric Psychiatry, 14*(8), 659-667.

Hirschman, K. B., Kapo, J. M., & Karlawish, J. (2008). Identifying the factors that facilitate or hinder advance planning by persons with dementia. *Alzheimer Disease & Associated Disorders, 22*(3), 293-298.

Hirschman, K. B., Xie, S. X., Feudtner, C., & Karlawish, J. (2004). How does an Alzheimer's disease patient's role in medical decision making change over time? *J Geriatr Psychiatry Neurol, 17*(2), 55-60. doi:10.1177/0891988704264540

Hoe, J., Katona, C., Orrell, M., & Livingston, G. (2007). Quality of life in dementia: care recipient and caregiver perceptions of quality of life in dementia: the LASER-AD study. *Int J Geriatr Psychiatry, 22*(10), 1031-1036. doi:10.1002/gps.1786

Hopp, F. P. (2000). Preferences for surrogate decision makers, informal communication, and advance directives among community-dwelling elders: results from a national study. *The Gerontologist, 40*(4), 449-457.

Horton-Deutsch, S., Twigg, P., & Evans, R. (2007). Health care decision-making of persons with dementia. *Dementia, 6*(1), 105-120. doi:10.1177/1471301207075643

Jaworska, A. (1997). *Rescuing Oblomov: A search for convincing justifications of value.* (PhD Dissertation), Harvard University.

Jaworska, A. (1999). Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philos Public Aff, 28*(2), 105-138.

Jensen-Dahm, C., Vogel, A., Waldorff, F. B., & Waldemar, G. (2012). Discrepancy between self- and proxy-rated pain in Alzheimer's disease: results from the Danish Alzheimer Intervention Study. *J Am Geriatr Soc, 60*(7), 1274-1278. doi:10.1111/j.1532-5415.2012.04036.x

Johnson, K. A., Minoshima, S., Bohnen, N. I., Donohoe, K. J., Foster, N. L., Herscovitch, P., . . . Amyloid Imaging, T. (2013). Appropriate use criteria for amyloid PET: a report of the Amyloid Imaging Task Force, the Society of Nuclear Medicine and Molecular Imaging, and the Alzheimer's Association. *Alzheimers Dement, 9*(1), e-1-16. doi:10.1016/j.jalz.2013.01.002

Jowsey, T., Yen, L., Wells, R., & Leeder, S. (2011). National Health and Hospital Reform Commission final report and patient-centred suggestions for reform. *Aust J Prim Health, 17*(2), 162-168. doi:10.1071/py10033

Jox, R. J., Denke, E., Hamann, J., Mendel, R., Forstl, H., & Borasio, G. D. (2012). Surrogate decision making for patients with end-stage dementia. *Int J Geriatr Psychiatry, 27*(10), 1045-1052. doi:10.1002/gps.2820

Judge, K. S., Menne, H. L., & Whitlatch, C. J. (2010). Stress process model for individuals with dementia. *Gerontologist, 50*(3), 294-302. doi:10.1093/geront/gnp162

Judge, K. S., Yarry, S. J., & Orsulic-Jeras, S. (2010). Acceptability and feasibility results of a strength-based skills training program for dementia caregiving dyads. *Gerontologist, 50*(3), 408-417. doi:10.1093/geront/gnp138

Kaldjian, L. C., Shinkunas, L. A., Bern-Klug, M., & Schultz, S. K. (2010). Dementia, goals of care, and personhood: a study of surrogate decision makers' beliefs and values. *Am J Hosp Palliat Care, 27*(6), 387-397. doi:10.1177/1049909109358660

Kapp, M. B. (2002). Decisional capacity in theory and practice: legal process versus 'bumbling through'. *Aging Ment Health, 6*(4), 413-417. doi:10.1080/1360786021000007054

Karel, M. J., Gurrera, R. J., Hicken, B., & Moye, J. (2010). Reasoning in the capacity to make medical decisions: the consideration of values. *Journal of Clinical Ethics, 21*(1), 58-71.

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. *J Aging Health, 19*(1), 123-151. doi:10.1177/0898264306296394

Karlawish, J. (2008). Measuring decision-making capacity in cognitively impaired individuals. *Neurosignals, 16*(1), 91-98. doi:10.1159/000109763

Karlawish, J., Casarett, D., Propert, K. J., James, B. D., & Clark, C. M. (2002). Relationship between Alzheimer's Disease Severity and Patient Participation in Decisions about Their Medical Care. *Journal of Geriatric Psychiatry and Neurology, 15*(2), 68-72. doi:10.1177/089198870201500203

Keady, J., Williams, S., & Hughes-Roberts, J. (2009). Analysing decision-making: Bridging and balancing. In D. O'Connor & B. Purves (Eds.), *Decision-Making, Personhood, and Dementia: Exploring the Interface* (pp. 147-158). London, UK: Jessica Kingsley Publishers.

Kensinger, E. A. (2009). Cognition in Aging and Age-Related Disease. *Encyclopedia of Neuroscience*, 1055-1061.

Kim, S. Y., Karlawish, J. H., Kim, H. M., Wall, I. F., Bozoki, A. C., & Appelbaum, P. S. (2011). Preservation of the capacity to appoint a proxy decision maker: implications for dementia research. *Archives of General Psychiatry, 68*(2), 214-220.

Kitwood, T. (1990). The dialectics of dementia: with particular reference to Alzheimer's disease. *Ageing and Society, 10*(2), 177-196.

Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society, 12*, 269-287.

Koppelman, E. R. (2002). Dementia and dignity: towards a new method of surrogate decision making. *J Med Philos, 27*(1), 65-85. doi:10.1076/jmep.27.1.65.2971

Kwok, T., Twinn, S., & Yan, E. (2007). The attitudes of Chinese family caregivers of older people with dementia towards life sustaining treatments. *J Adv Nurs, 58*(3), 256-262. doi:10.1111/j.1365-2648.2007.04230.x

Laakkonen, M. L., Raivio, M. M., Eloniemi-Sulkava, U., Tilvis, R. S., & Pitkala, K. H. (2008). Disclosure of dementia diagnosis and the need for advance care planning in individuals with Alzheimer's disease. *J Am Geriatr Soc, 56*(11), 2156-2157. doi:10.1111/j.1532-5415.2008.01987.x

Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology: Psychological Sciences, 44*(3), 61-71.

Lee, C. S., Vellone, E., Lyons, K. S., Cocchieri, A., Bidwell, J. T., D'Agostino, F., . . . Riegel, B. (2015). Patterns and predictors of patient and caregiver engagement in heart failure care: A multi-level dyadic study. *Int J Nurs Stud, 52*(2), 588-597. doi:10.1016/j.ijnurstu.2014.11.005

Lingler, J. H., Hirschman, K. B., Garand, L., Dew, M. A., Becker, J. T., Schulz, R., & DeKosky, S. T. (2008). Frequency and correlates of advance planning among cognitively impaired older adults. *The American Journal of Geriatric Psychiatry, 16*(8), 643-649.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (2002). Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine, 64*, 510-519.

Logsdon, R. G., Pike, K. C., McCurry, S. M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010). Early-stage memory loss support groups: outcomes from a randomized controlled clinical trial. *J Gerontol B Psychol Sci Soc Sci, 65*(6), 691-697. doi:10.1093/geronb/gbq054

Long, K., Sudha, S., & Mutran, E. J. (1998). Elder-proxy agreement concerning the functional status and medical history of the older person: The impact of caregiver burden and depressive symptomatology. *Journal of the American Geriatrics Society, 46*(9), 1103-1111.

Lopez, R. P., & Guarino, A. J. (2011). Uncertainty and decision making for residents with dementia. *Clin Nurs Res, 20*(3), 228-240. doi:10.1177/1054773811405521

Lyons, K. S., & Sayer, A. G. (2005a). Longitudinal dyad models in family research. *Journal of Marriage and the Family, 67*, 1048-1060.

Lyons, K. S., & Sayer, A. G. (2005b). Using multilevel modeling in caregiving research. *Aging Ment Health, 9*(3), 189-195. doi:10.1080/13607860500089831

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: Psychological Sciences, 57B*(3), 195-204.

MacQuarrie, C. R. (2005). Experiences in early stage Alzheimer's disease: understanding the paradox of acceptance and denial. *Aging Ment Health, 9*(5), 430-441. doi:10.1080/13607860500142853

Mak, W. (2011). Self-reported goal pursuit and purpose in life among people with dementia. *J Gerontol B Psychol Sci Soc Sci, 66*(2), 177-184. doi:10.1093/geronb/gbq092

McCormack, B. (2002). The person of the voice: narrative identities in informed consent. *Nursing Philosophy, 3*, 114-119.

McCormack, B., & McCance, T. V. (2006). Development of a framework for person-centred nursing. *J Adv Nurs, 56*(5), 472-479. doi:10.1111/j.1365-2648.2006.04042.x

McPherson, C. J., & Addington-Hall, J. M. (2003). Judging the quality of care at the end of life: can proxies provide reliable information? *Social Science & Medicine, 56*, 95-109.

Menne, H. L., Judge, K. S., & Whitlatch, C. J. (2009). Predictors of quality of life for individuals with dementia: Implications for intervention. *Dementia, 8*(4), 543-560. doi:10.1177/1471301209350288

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 & Other Dementias, 23*(1), 23-29.

Menne, H. L., & Whitlatch, C. J. (2007). Decision-making involvement of individuals with dementia. *The Gerontologist, 47*(6), 810-819.

Miller, L. M., Lyons, K. S., & Bennett, J. A. (2015). Incongruent perceptions of pain and physical function among families living with lung cancer. *Support Care Cancer, 23*(9), 2755-2762. doi:10.1007/s00520-015-2640-x

Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2014). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia, E-pub ahead of print*(3 November 2014). doi:10.1177/1471301214555542

Mitchell, A. J. (2009). A meta-analysis of the accuracy of the mini-mental state examination in the detection of dementia and mild cognitive impairment. *J Psychiatr Res, 43*(4), 411-431. doi:10.1016/j.jpsychires.2008.04.014

Moon, H., & Adams, K. B. (2013). The effectiveness of dyadic interventions for people with dementia and their caregivers. *Dementia (London), 12*(6), 821-839. doi:10.1177/1471301212447026

Moon, H., Townsend, A., Whitlatch, C. J., & Dilworth-Anderson, P. (in press). Quality of life for dementia caregiving dyads: Effects of incongruent perceptions of everyday care and values. *Gerontologist, in press*.

Moye, J., Karel, M. J., Gurrera, R. J., & Azar, A. R. (2006). Neuropsychological predictors of decision-making capacity over 9 months in mild-to-moderate dementia. *J Gen Intern Med, 21*(1), 78-83. doi:10.1111/j.1525-1497.2005.00288.x

Moye, J., & Marson, D. C. (2007). Assessment of decision-making capacity in older adults: An emerging area of practice and research. *Journal of Gerontology: Psychological Sciences, 62B*(1), 3-11.

Moyle, W., Murfield, J. E., Griffiths, S. G., & Venturato, L. (2012). Assessing quality of life of older people with dementia: a comparison of quantitative self-report and proxy accounts. *J Adv Nurs, 68*(10), 2237-2246. doi:10.1111/j.1365-2648.2011.05912.x

Murphy, J., & Oliver, T. (2013). The use of Talking Mats to support people with dementia and their carers to make decisions together. *Health Soc Care Community, 21*(2), 171-180. doi:10.1111/hsc.12005

Nelis, S. M., Clare, L., Martyr, A., Markova, I., Roth, I., Woods, R. T., . . . Morris, R. G. (2011). Awareness of social and emotional functioning in people with early-stage dementia and implications for carers. *Aging Ment Health, 15*(8), 961-969. doi:10.1080/13607863.2011.575350

Nilsson, A., Rasmussen, B. H., & Edvardsson, D. (2013). Falling behind: a substantive theory of care for older people with cognitive impairment in acute settings. *J Clin Nurs, 22*(11-12), 1682-1691. doi:10.1111/jocn.12177

O'Connor, D., Purves, B., & Downs, M. (2009). Decision-Making and Dementia: Towards a Social Model of Understanding. In D. O'Connor & B. Purves (Eds.), *Decision-Making, Personhood, and Dementia: Exploring the Interface* (pp. 203-214). London, UK: Jessica Kingsley Publishers.

Orfei, M. D., Varsi, A. E., Blundo, C., Celia, E., Casini, A. R., Caltagirone, C., & Spalletta, G. (2010). Anosognosia in mild cognitive impairment and mild Alzheimer's disease:

frequency and neuropsychological correlates. *Am J Geriatr Psychiatry, 18*(12), 1133-1140. doi:10.1097/JGP.0b013e3181dd1c50

Parmelee, P. A., Lawton, M. P., & Katz, I. R. (1989). Psychometric properties of the Geriatric Depression Scale among the institutionalized aged. *Psychological Assessment, 1*, 331-338.

Pasman, H. R., Onwuteaka-Philipsen, B. D., Ooms, M. E., van Wigcheren, P. T., van der Wal, G., & Ribbe, M. W. (2004). Forgoing artificial nutrition and hydration in nursing home patients with dementia: patients, decision making, and participants. *Alzheimer Disease & Associated Disorders, 18*(3), 154-162.

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

Penrod, J., Yu, F., Kolanowski, A., Fick, D. M., Loeb, S. J., & Hupcey, J. E. (2007). Reframing person-centered nursing care for persons with dementia. *Res Theory Nurs Pract, 21*(1), 57-72.

Perrin, R. J., Craig-Schapiro, R., Malone, J. P., Shah, A. R., Gilmore, P., Davis, A. E., . . . Fagan, A. M. (2011). Identification and validation of novel cerebrospinal fluid biomarkers for staging early Alzheimer's disease. *PLoS One, 6*(1), e16032. doi:10.1371/journal.pone.0016032

Phelan, E. A., Borson, S., Grothaus, L., Balch, S., & Larson, E. B. (2012). Association of incident dementia with hospitalizations. *JAMA, 307*(2), 165-172. doi:10.1001/jama.2011.1964

Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. *J Gerontol B Psychol Sci Soc Sci, 61*(1), P33-45.

Poole, M., Bond, J., Emmett, C., Greener, H., Louw, S. J., Robinson, L., & Hughes, J. C. (2014). Going home? An ethnographic study of assessment of capacity and best interests in people with dementia being discharged from hospital. *BMC Geriatrics, 14*(56), 1-15.

Poulshock, S. W., & Deimling, G. T. (1984). Families caring for elders in residence: issues in the measurement of burden. *J Gerontol, 39*(2), 230-239.

Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: A systematic review and meta-analysis. *Alzheimers Dement, 9*(1), 63-75 e62. doi:10.1016/j.jalz.2012.11.007

Prince, M., Bryce, R., & Ferri, C. P. (2011). World Alzheimer report 2011: the benefits of early diagnosis and intervention. *Alzheimer's Disease International.*

Raudenbush, S. W., Bryk, A. S., & Congdon, R. (2011). HLM for Windows (Version 7). Skokie, IL: Scientific Software International, Inc.

Reamy, A. M., Kim, K., Zarit, S. H., & Whitlatch, C. J. (2011). Understanding discrepancy in perceptions of values: individuals with mild to moderate dementia and their family caregivers. *Gerontologist, 51*(4), 473-483. doi:10.1093/geront/gnr010

Reamy, A. M., Kim, K., Zarit, S. H., & Whitlatch, C. J. (2013). Values and preferences of individuals with dementia: perceptions of family caregivers over time. *Gerontologist, 53*(2), 293-302. doi:10.1093/geront/gns078

Roberts, J. S., & Silverio, E. (2009). Evaluation of an education and support program for early-stage Alzheimer's disease. *Journal of Applied Gerontology, 28*(4), 419-435.

Robinson, L., Dickinson, C., Bamford, C., Clark, A., Hughes, J., & Exley, C. (2013). A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, 'a good idea in theory but ...'. *Palliat Med, 27*(5), 401-408. doi:10.1177/0269216312465651

Robinson, L., Dickinson, C., Rousseau, N., Beyer, F., Clark, A., Hughes, J., . . . Exley, C. (2012). A systematic review of the effectiveness of advance care planning interventions for people with cognitive impairment and dementia. *Age Ageing, 41*(2), 263-269. doi:10.1093/ageing/afr148

Rowe, C. C., Bourgeat, P., Ellis, K. A., Brown, B., Lim, Y. Y., Mulligan, R., . . . Villemagne, V. L. (2013). Predicting Alzheimer disease with beta-amyloid imaging: results from the Australian imaging, biomarkers, and lifestyle study of ageing. *Ann Neurol, 74*(6), 905-913. doi:10.1002/ana.24040

Sabat, S. R. (2005). Capacity for decision-making in Alzheimer's disease: selfhood, positioning and semiotic people. *Australian & New Zealand Journal of Psychiatry, 39*(11-12), 1030-1035.

Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers. *Int Psychogeriatr, 25*(6), 949-961. doi:10.1017/S1041610213000306

Sands, L. P., Ferreira, P., Stewart, A. L., Brod, M., & Yaffe, K. (2004). What explains differences between dementia patients' and their caregivers' ratings of patients' quality of life? *American Journal of Geriatric Psychiatry, 12*(3), 272-280.

Sayer, A. G., & Klute, M. M. (2005). Analyzing couples and families: Multilevel methods. In V. L. Bengtson, A. C. Acock, K. R. Allen, P. Dilworth-Anderson, & D. M. Klein (Eds.), *Sourcebook of Family Theory and Research* (pp. 289-313). Thousand Oaks, CA: Sage Publications.

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing, 108*(9), 23-27.

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*(6), 741-751.

Shalowitz, D. I., Garrett-Mayer, E., & Wendler, D. (2006). The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med, 166*(5), 493-497. doi:10.1001/archinte.166.5.493

Shankar, K. N., Hirschman, K. B., Hanlon, A. L., & Naylor, M. D. (2014). Burden in caregivers of cognitively impaired elderly adults at time of hospitalization: a cross-sectional analysis. *J Am Geriatr Soc, 62*(2), 276-284. doi:10.1111/jgs.12657

Silverstein, N. M., & Sherman, R. (2010). Taking control of Alzheimer's disease: a training evaluation. *Gerontol Geriatr Educ, 31*(3), 274-288. doi:10.1080/02701960.2010.503136

Smebye, K. L., Kirkevold, M., & Engedal, K. (2012). How do persons with dementia participate in decision making related to health and daily care? a multi-case study. *BMC Health Serv Res, 12*, 241. doi:10.1186/1472-6963-12-241

Smith, A. K., Lo, B., & Sudore, R. (2013). When previously expressed wishes conflict with best interests. *JAMA Intern Med, 173*(13), 1241-1245. doi:10.1001/jamainternmed.2013.6053

Sörensen, S., Mak, W., & Pinquart, M. (2011). Planning and decision making for care transitions. *Annual Review of Gerontology and Geriatrics, 31*(1), 111-142.

Specht, J. K., Taylor, R., & Bossen, A. L. (2009). Partnering for care: the evidence and the expert. *J Gerontol Nurs, 35*(3), 16-22.

St-Amant, O., Ward-Griffin, C., DeForge, R. T., Oudshoorn, A., McWilliam, C., Forbes, D., . . . Hall, J. (2012). Making care decisions in home-based dementia care: why context matters. *Can J Aging, 31*(4), 423-434. doi:10.1017/S0714980812000396

Stein-Parbury, J., Chenoweth, L., Jeon, Y. H., Brodaty, H., Haas, M., & Norman, R. (2012). Implementing Person-Centered Care in Residential Dementia Care. *Clinical Gerontologist, 35*(5), 404-424.

Swidler, R. N., Seastrum, T., & Shelton, W. (2007). Difficult hospital inpatient discharge decisions: ethical, legal and clinical practice issues. *Am J Bioeth, 7*(3), 23-28. doi:10.1080/15265160601171739

Teri, L., & Wagner, A. W. (1991). Assessment of depression in patients with Alzheimer's disease: concordance among informants. *Psychology and Aging, 6*(2), 280-285.

Thies, W., & Bleiler, L. (2013). 2013 Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 9*(2), 208-245.

Tombaugh, T. M., & McIntyre, N. J. (1992). The Mini-Mental State Examination: a comprehensive review. *J Am Geriatr Soc, 40*, 922-935.

Triplett, P., Black, B. S., Phillips, H., Richardson Fahrendorf, S., Schwartz, J., Angelino, A. F., . . . Rabins, P. V. (2008). Content of advance directives for individuals with advanced dementia. *J Aging Health, 20*(5), 583-596. doi:10.1177/0898264308317822

Tsou, A. Y., & Karlawish, J. (2014). Ethical, legal, and social issues in dementia. In J. F. Quinn (Ed.), *Dementia* (pp. 137-149). West Sussex, UK: John Wiley & Sons.

Tyrrell, J., Genin, N., & Myslinski, M. (2006). Freedom of choice and decision-making in health and social care: Views of older patients with early-stage dementia and their carers. *Dementia, 5*(4), 479-502. doi:10.1177/1471301206069915

Van't Leven, N., Prick, A. E., Groenewoud, J. G., Roelofs, P. D., de Lange, J., & Pot, A. M. (2013). Dyadic interventions for community-dwelling people with dementia and their family caregivers: a systematic review. *Int Psychogeriatr, 25*(10), 1581-1603. doi:10.1017/S1041610213000860

Vernooij-Dassen, M., & Moniz-Cook, E. (2016). Person-centred dementia care: moving beyond caregiving. *Aging Ment Health*, 1-2. doi:10.1080/13607863.2016.1154017

Weiner, M. F., Svetlik, D., & Risser, R. C. (1997). What depressive symptoms are reported in Alzheimer's patients? *International Journal of Geriatric Psychiatry, 12*, 648-652.

Whitlatch, C. J., Feinberg, L. F., & Tucke, S. S. (2005a). Accuracy and consistency of responses from persons with cognitive impairment. *Dementia, 4*(2), 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 families. *The Gerontologist, 45*(3), 370-380.

Whitlatch, C. J., Judge, K., Zarit, S. H., & Femia, E. (2006). Dyadic intervention for family caregivers and care receivers in early-stage dementia. *Gerontologist, 46*(5), 688-694.

Whitlatch, C. J., Piiparinen, R., & Feinberg, L. F. (2009). How well do family caregivers know their relatives' care values and preferences? *Dementia, 8*(2), 223-243. doi:10.1177/1471301209103259

Winters-Stone, K. M., Lyons, K. S., Bennett, J. A., & Beer, T. M. (2014). Patterns and predictors of symptom incongruence in older couples coping with prostate cancer. *Support Care Cancer, 22*(5), 1341-1348. doi:10.1007/s00520-013-2092-0

Wolff, J. L., Roter, D. L., Given, B., & Gitlin, L. N. (2009). Optimizing patient and family involvement in geriatric home care. *Journal for Healthcare Quality, 31*(2), 24-33.

Wolfs, C. A., de Vugt, M. E., Verkaaik, M., Haufe, M., Verkade, P. J., Verhey, F. R., & Stevens, F. (2012). Rational decision-making about treatment and care in dementia: a contradiction in terms? *Patient Educ Couns, 87*(1), 43-48. doi:10.1016/j.pec.2011.07.023

Woods, R. T. (2001). Discovering the person with Alzheimer's disease: Cognitive, emotional and behavioural aspects. *Aging and Mental Health, 5*(SUPPL. 1), S7-S16.

Zarit, S. H., Femia, E. E., Watson, J., Rice-Oeschger, L., & Kakos, B. (2004). Memory Club: a group intervention for people with early-stage dementia and their care partners. *Gerontologist, 44*(2), 262-269.

Table 2. 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 3: Level 1 and level 2 multivariate outcomes model: Perceptions of the PWD's decision-making involvement (N = 42 dyads)

Fixed effects (robust SE)	Level 1 Model			Level 2 Model		
	β	SE	t	β	SE	t
Patient intercept	2.11	.10	21.10***	2.09	.08	24.83***
Patient's Cognitive Impairment				.07	.03	2.87**
Family's Care-Related Strain				-.02	.03	-0.69
Family's Perception of PWD's Autonomy				.43	.15	2.85**
Family's Perception of Relationship Strain				-.20	.11	-1.84
Family member intercept	2.09	.10	21.20***	2.09	.08	26.47***
Patient's Cognitive Impairment				.02	.02	1.14
Family's Care-Related Strain				.05	.03	1.58
Family's Perception of PWD's Autonomy				.74	.16	4.75***
Family's Perception of Relationship Strain				-.21	.09	-2.17*
Random Effects	Variance Component		χ^2	Variance Component		χ^2
Patient	.37		351.02***	.23		217.38***
Family member	.35		327.01***	.19		191.26***

****p*< .001; ***p*< .01; **p*< .05. PWD= person with dementia

Table 4. Level 1 Models. Perceptions of the PWD's Care Values: Dyadic Means and Incongruence Scores

	Autonomy			Burden			Safety/Quality of Care			Social Interactions		
Fixed effects	β	SE	*df*	β	SE	*df*	β	SE	*df*	β	SE	*df*
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 5. Level 2 Models. Determinants of Incongruence in Perceptions of the PWD's Care Values

	Autonomy			Burden			Safety/Quality of Care		
Fixed effects	β	SE	*df*	β	SE	*df*	β	SE	*df*
Slope (incongruence)[a]	-.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.

Title: Shared decision-making in dementia: A review of patient and family carer involvement:

Author: Lyndsey M. Miller, Carol J. Whitlatch, Karen S. Lyons

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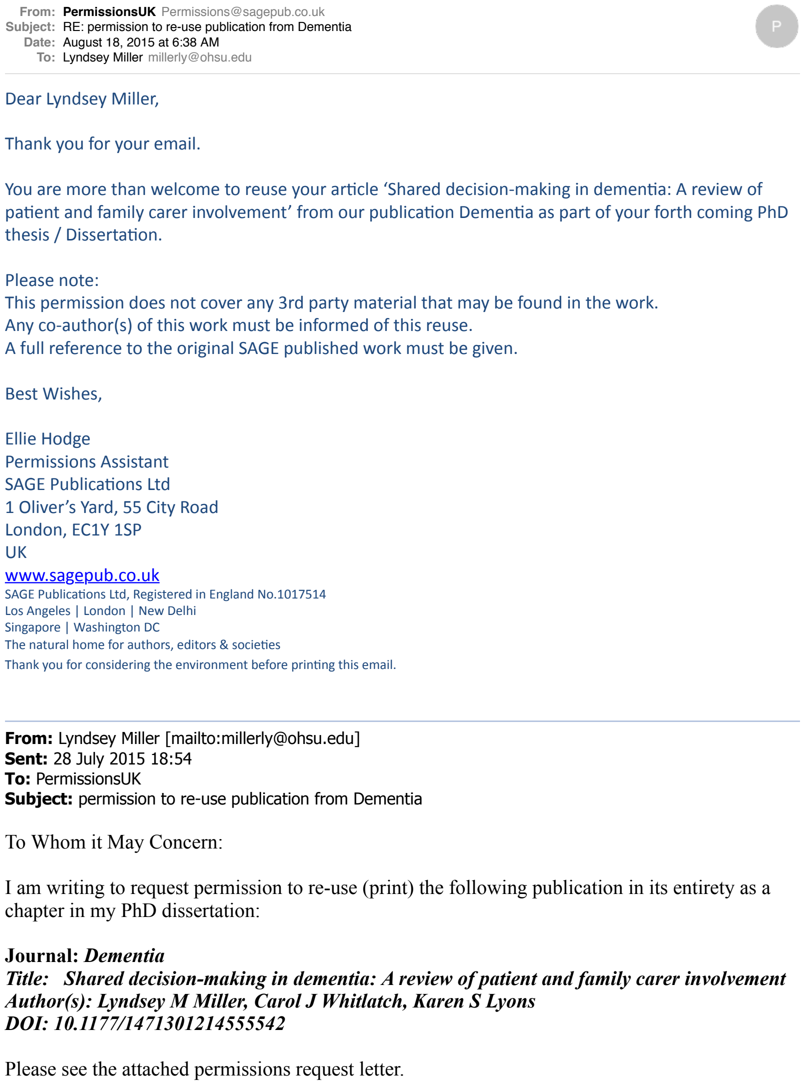

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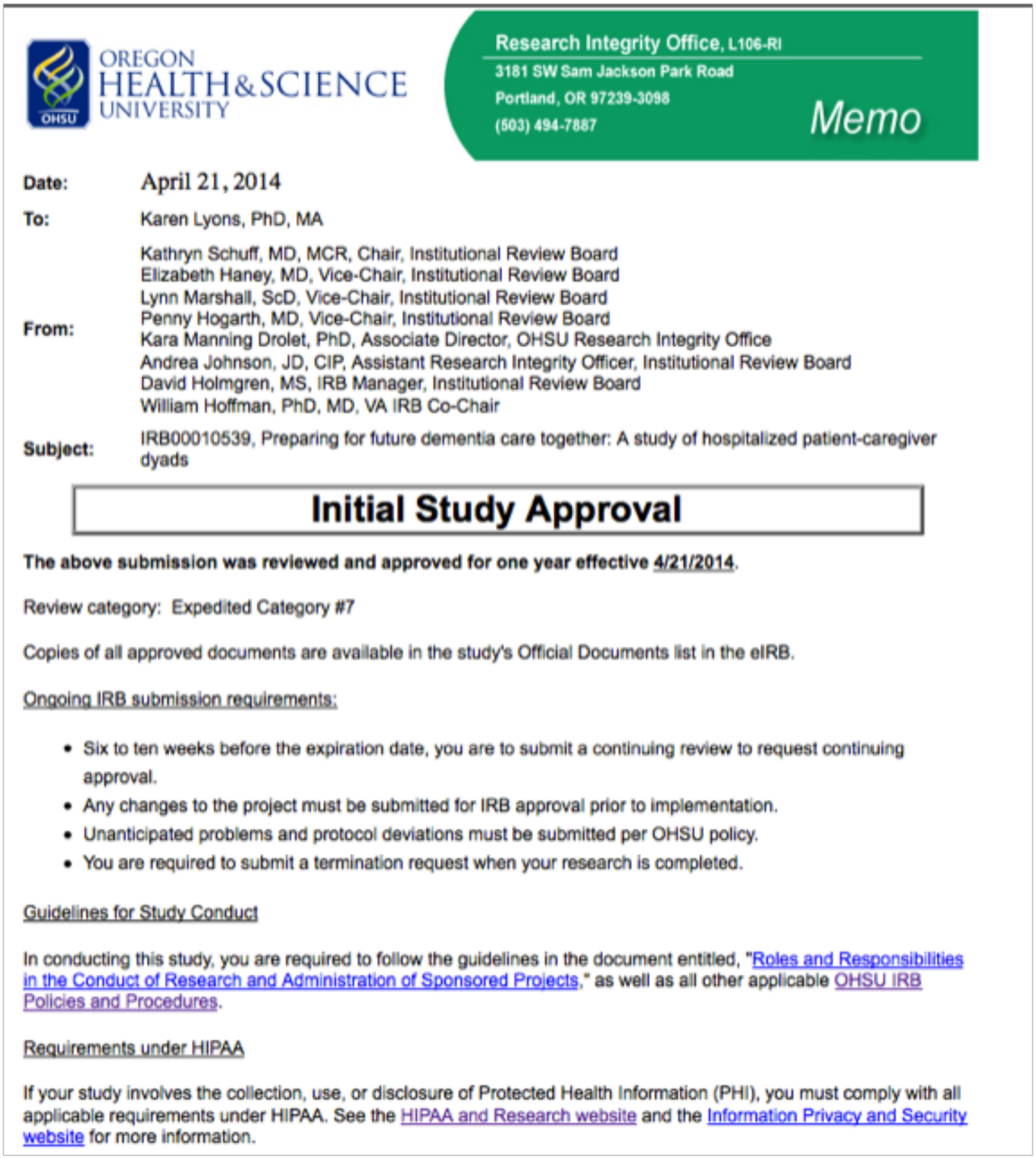

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Memo

Date: April 21, 2014

To: Karen Lyons, PhD, MA

From:
Kathryn Schuff, MD, MCR, Chair, Institutional Review Board
Elizabeth Haney, MD, Vice-Chair, Institutional Review Board
Lynn Marshall, ScD, Vice-Chair, Institutional Review Board
Penny Hogarth, MD, Vice-Chair, Institutional Review Board
Kara Manning Drolet, PhD, Associate Director, OHSU Research Integrity Office
Andrea Johnson, JD, CIP, Assistant Research Integrity Officer, Institutional Review Board
David Holmgren, MS, IRB Manager, Institutional Review Board
William Hoffman, PhD, MD, VA IRB Co-Chair

Subject: IRB00010539, Preparing for future dementia care together: A study of hospitalized patient-caregiver dyads

Initial Study Approval

The above submission was reviewed and approved for one year effective 4/21/2014.

Review category: Expedited Category #7

Copies of all approved documents are available in the study's Official Documents list in the eIRB.

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- Any changes to the project must be submitted for IRB approval prior to implementation.
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Guidelines for Study Conduct

In conducting this study, you are required to follow the guidelines in the document entitled, "Roles and Responsibilities in the Conduct of Research and Administration of Sponsored Projects," as well as all other applicable OHSU IRB Policies and Procedures.

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Memo

Date:	April 2, 2015
To:	Karen Lyons, PhD, MA
From:	Kathryn Schuff, MD, MCR, Chair, Institutional Review Board Elizabeth Haney, MD, Vice-Chair, Institutional Review Board Lynn Marshall, ScD, Vice-Chair, Institutional Review Board Penny Hogarth, MD, Vice-Chair, Institutional Review Board Kara Manning Drolet, PhD, Associate Director, OHSU Research Integrity Office Andrea Johnson, JD, CIP, Assistant Research Integrity Officer, Institutional Review Board David Holmgren, MS, IRB Manager, Institutional Review Board William Hoffman, PhD, MD, VA IRB Co-Chair
IRB #:	IRB00010539
Study Title:	Preparing for future dementia care together: A study of hospitalized patient-caregiver dyads
Modification ID:	MR00044828
Modification Name:	Adds chart review for recruitment purposes only

Modification Approval

The above submission was reviewed and approved on 4/2/2015 .

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Guidelines for Study Conduct

Research Consent Summary

You are being asked to join a research study. You do not have to join the study. Even if you decide to join now, you can change your mind later. There is an additional optional part of this study. You may participate in the main study without participating in the optional part.

1. The purpose of this study is to learn more about how families plan for future dementia care.
2. We want to learn:
    a. About your decision-making involvement, values and preferences for everyday care (routines at home)
    b. About the relationship between your values and preferences and your health and wellbeing
    c. About your family member's caregiving role now and in the future
3. Everyone who joins the study will complete a survey.
4. If you join the study, you will complete a survey once in private in your hospital room.
5. Risks: 1) There is a possibility that you may find some questions emotionally difficult or distressing to complete. You may refuse to answer any of the questions that you do not wish to answer. You may choose to complete some of the questions at a later time.
   2) Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality.
6. If you agree, information collected during the study may be saved for future research. This information will be *de-identified*. De-identified means that your name and any other personal identifying information will be removed before it is saved.

OREGON
HEALTH & SCIENCE
UNIVERSITY

IRB#: 00010539

Research Consent and Authorization Form (Patient Participant)

TITLE: Preparing for Future Dementia Care Together

PRINCIPAL INVESTIGATOR:	Karen S. Lyons, PhD	(503) 494-3975
CO-INVESTIGATORS:	Lyndsey M. Miller, RN PhD Student	(971) 239-8191
	Christopher S. Lee, RN PhD	(503) 278-9073

FUNDED BY: National Institute for Nursing Research # 1F31NR015195-01

CONFLICT OF INTEREST: No conflicts of interest.

PURPOSE: You have been invited to be in this research study because you are a person with dementia who has been admitted to the hospital. The purpose of this study is to learn more about your perspective on how families plan for future dementia care.

This study requires you to complete one survey today, while you are in the hospital. The survey will take approximately 38 minutes. We are also asking you if we may save information that we collect during this study. If you give us permission, we will store it indefinitely in a data repository for future research. This saved information will be *de-identified*. De-identified means that your name and any other personal identifying information will be removed before it is saved. Participation in the data repository is optional – you do not need to agree to let your information be used for future research to participate in this study.

We expect to enroll 60 participants who have been admitted to Oregon Health & Science University (OHSU) Hospital and 60 corresponding family members (1 per person admitted to the hospital), for a total of 120 participants.

PROCEDURES:
We will ask you to complete a survey today. The survey will ask you questions about:

1. Your background and how you are related to the family member who is also participating
2. Your general health, wellbeing, and daily activities
3. Your values and preferences about receiving care for your daily life
4. Your relationship with your family member who provides the most care for you
5. Your involvement in making decisions

If you choose to participate, you can complete the survey here in private in your hospital room. You may take breaks during the survey. If you prefer, we will modify the survey to complete it in multiple sessions.

We are also asking you if you are willing to let qualified researchers use de-identified information from these surveys for future caregiving research studies. The information will be labeled as described in the **CONFIDENTIALITY** section. This is optional. At the end of this form, there is a section where you can tell us whether or not you agree to let us do this.

If you have any questions regarding this study now or in the future, please contact the Principal Investigator, **Karen S. Lyons**, PhD, at (503) 494-3975**.**

RISKS AND DISCOMFORTS:
Some of the survey questions may seem personal or you may become fatigued when answering them. There is also a possibility that you may find some questions distressing. You may refuse to answer any of the questions that you do not wish to answer. You may also choose to complete some of the questions at a later time.

Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality.

BENEFITS:
You will not personally benefit from being in this study. However, by serving as a research participant, you may help us learn how to benefit families planning for dementia care in the future.

ALTERNATIVES:
You may choose not to be in this study. You may choose not to answer particular questions. You may discontinue your participation in this study at any time.

CONFIDENTIALITY:
We will take steps to keep your personal information confidential. We will not share your name or identity with anyone outside this study unless we have your special permission. We will never use your name or identity for publication or publicity. Although we cannot guarantee a breach of privacy, we take special precautions to prevent it:

1. The survey you complete as part of this study is coded so that none of your identifying information is recorded in the survey. This means that we immediately remove any identifying information and label them with a unique code that does not contain any personal identifiers. De-identified surveys are kept on a password-

protected computer and encrypted database, separate from the code list that links your identity to the survey.
2. This signed consent form is kept in a locked file cabinet in a locked office in a secure building.
3. We maintain one file that contains personal information and study codes (your name, address, and phone numbers) so that we can follow up with you during your participation in this study. This file is double-password-protected and encrypted. Only the principle investigator has access to this file.
4. Information will only be placed in a data repository for use in possible future research if you indicate your agreement at the end of this form. Information saved for future research also contains no personal identifiers. The investigators, study staff, and others at OHSU may use the information we collect and create about you in order to conduct and oversee this research study and, if you permit, to conduct future research.

We may release your information to others outside of OHSU who are involved in conducting or overseeing research, including:

- The Office for Human Research Protections, a federal agency that oversees research involving humans

We will not release information about you to others not listed above, unless required or permitted by law. We will not use your name or your identity for publication or publicity purposes.

When we send information outside of OHSU, it may no longer be protected under federal or Oregon law. In this case, your information could be used and re-released without your permission.

Data from this study may be shared with other investigators for future research studies. All identifying information about you will be removed from the data before they are released to any other investigators.

We may continue to use and disclose your information as described above indefinitely.

Under Oregon Law, suspected elder abuse must be reported to appropriate authorities.

COMMERCIAL DEVELOPMENT:

Information about you or obtained from you in this research may be used for commercial purposes, such as making a discovery that could be patented or licensed to a company. There are no plans to pay you if this happens. You will not have any property rights or ownership or financial interest in or arising from products or data that may result from your participation in this study. Further, you will have no responsibility or liability for any use that may be made of your samples or information.

COSTS:

There will be no cost to you or your insurance company to participate in this study.

LIABILITY:

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact the study Principal Investigator, **Karen S. Lyons**, PhD, at (503) 494-3975**.**

You have not waived your legal rights by signing this form. If you are harmed by the study procedures, you will be treated. Oregon Health & Science University does not offer to pay for the cost of the treatment. Any claim you make against Oregon Health & Science University may be limited by the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:

If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. You do not have to allow the use and disclosure of your health information in the study, but if you do not, you cannot be in the study. A part of this study (data repository for use in future research) is optional. You can still participate in the main part of the study even if you choose not to participate in this optional part.

If you do join the study and later change your mind, you have the right to quit at any time. This includes the right to withdraw your authorization to use and disclose your health information. You can choose to withdraw from the optional part of this study (data repository) without withdrawing from the whole study. If you choose not to join any or all parts of this study, or if you withdraw early from any or all parts of the study, there will be no penalty or loss of benefits to which you are otherwise entitled, including being able to receive health care services or insurance coverage for services. Talk to the investigator if you want to withdraw from the whole study or the optional part of the study.

If you no longer want your health information to be used and disclosed as described in this form, you must send a written request or email stating that you are revoking your authorization to:

Karen S. Lyons, PhD
Oregon Health and Science University School of Nursing
Mail Code: SN-ORD
3455 SW US Veterans Hospital Rd.
Portland, OR 97239-2941
email: lyonsk@ohsu.edu

Your request will be effective as of the date we receive it. However, health information collected before your request is received may continue to be used and disclosed to the extent that we have already acted based on your authorization.

You may be removed from the study if: the Principal Investigator stops the study, or at the discretion of the Principal Investigator.

We may give you new information during the course of this research study that might change the way you feel about being in the study.

SIGNATURES:

OPTIONAL PORTION OF STUDY

The optional portion of this study (data repository) is described in detail throughout this consent form and listed here as a summary. Please read the option below and place your initials next to it if you choose to participate. You can still participate in the main part of the study even if you choose not to participate in this optional part.

_____ I give my consent for my survey information to be stored in a repository and used for future research studies.

Your signature below indicates that you have read this entire form and that you agree to be in this study.

We will give you a copy of this signed form.

OREGON HEALTH & SCIENCE UNIVERSITY
INSTITUTIONAL REVIEW BOARD
PHONE NUMBER (503) 494-7887
CONSENT/AUTHORIZATION FORM APPROVAL DATE

Jul. 28, 2014

Do not sign this form after the
expiration date of: Apr. 20, 2015

Participant Printed Name ________ Participant Signature ________ Date ________

Person Obtaining Consent Printed Name ________ Person Obtaining Consent Signature ________ Date ________

IRB#: 10539

Preparing for Future Dementia Care Together

Participant (Family Member)

Consent and Authorization

Research Consent Summary

You are being asked to join a research study. You do not have to join the study. Even if you decide to join now, you can change your mind later. There is an additional optional part of this study. You may participate in the main study without participating in the optional part.

7. The purpose of this study is to learn more about how families plan for future dementia care.
8. We want to learn:
    a. About the values and preferences of people with dementia for their everyday care (routines at home)
    b. About how values and preferences are related to the health and wellbeing of you and your family member
    c. About your caregiving role now and in the future.
9. Everyone who joins the study will complete a survey.
10. If you join the study, you will complete a survey once. You will complete the survey in person in a private room here in the hospital.
11. Risks: 1) There is a possibility that you may find some questions emotionally difficult or distressing. You may refuse to answer any of the questions that you do not wish to answer. You may also choose to complete the questions at a later time. 2) Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality.
12. If you agree, information collected during the study may be saved for future research. This information will be *de-identified*. De-identified information means that your name and any other personal identifying information will be removed before the information is saved.

IRB#: 00010539

Research Consent and Authorization Form (Family Member Participant)

TITLE: Preparing for Future Dementia Care Together

PRINCIPAL INVESTIGATOR:	Karen S. Lyons, PhD	(503) 494-3975
CO-INVESTIGATORS:	Lyndsey M. Miller, RN PhD Student	(971) 239-8191
	Christopher S. Lee, RN PhD	(503) 278-9073

FUNDED BY: National Institute for Nursing Research # 1F31NR015195-01

CONFLICT OF INTEREST: No conflicts of interest.

PURPOSE: You have been invited to be in this research study because you are a family caregiver of a person with dementia who has been admitted to the hospital. The purpose of this study is to learn more about how families plan for future dementia care.

This study requires you to complete one survey today, in a private room nearby. The survey will take approximately 35 minutes. We are also asking you if we may save information that we collect during this study and store it indefinitely in a data repository for future research. This saved information will be *de-identified*, which means that your name and any other personal identifying information will be removed. Participation in the data repository is optional – you do not need to agree to let your information be used for future research to participate in this study.

We expect to enroll 60 participants who have been admitted to Oregon Health & Science University (OHSU) Hospital and 60 corresponding family members (1 per person admitted to the hospital), for a total of 120 participants.

PROCEDURES:
We will ask you to complete a survey today. The survey will ask you questions about:

6. Your background and how you are related to the participant admitted to OHSU Hospital.
7. Your general health and wellbeing

8. Your understanding of the values and preferences that your family member holds for everyday care
9. Your relationship with your family member
10. Your family member's involvement in making decisions
11. Your caregiving experience
12. Your current feelings about preparing for future care of your family member

If you choose to participate, you will complete the survey here at the hospital in a private room. You may take breaks during the survey. If you prefer, we will modify the survey to complete it in multiple sessions.

We are also asking you if you are willing to let qualified researchers use de-identified information from these surveys for future caregiving research studies. The information will be labeled as described in the **CONFIDENTIALITY** section. This is optional. At the end of this form, there is a section where you can tell us whether or not you agree to let us do this.

If you have any questions regarding this study now or in the future, please contact the Principal Investigator, **Karen S. Lyons**, PhD, at (503) 494-3975**.**

RISKS AND DISCOMFORTS:
Some of the survey questions may seem personal or you may become fatigued when answering them. There is also a possibility that you may find some questions distressing. You may refuse to answer any of the questions that you do not wish to answer. You may choose to complete some of the questions at a later time.

Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality.

BENEFITS:
You will not personally benefit from being in this study. However, by serving as a research participant, you may help us learn how to benefit families planning for dementia care in the future.

ALTERNATIVES:
You may choose not to be in this study. You may choose not to answer particular questions. You may discontinue your participation in this study at any time.

CONFIDENTIALITY:
We will take steps to keep your personal information confidential. We will not share your name or identity with anyone outside this study unless we have your special permission. We will never use your name or identity for publication or publicity. Although we cannot guarantee a breach of privacy, we take special precautions to prevent it:

5. The survey you complete as part of this study is coded so that none of your identifying information is recorded in the survey. This means that we immediately remove any identifying information. We will label your survey with a unique code

that does not contain any personal identifiers. De-identified surveys are kept on a password-protected computer and encrypted database. Surveys will be kept separate from the code list that links your identity to the survey.

6. This signed consent form is kept in a locked file cabinet in a locked office in a secure building.
7. We maintain one file that contains personal information and study codes (your name, address, and phone numbers) so that we can follow up with you during your participation in this study. This file is double-password-protected and encrypted. Only the principle investigator has access to this file.
8. If you agree, information will also be placed in a data repository for use in future research. Information saved for future research also contains no personal identifiers. The investigators (Drs. Lyons, Lee, and Ms. Miller), may use the information we collect and create about you in order to conduct and oversee this research study. If you give us permission to store your information in the repository, we may also release this information to others at OHSU and outside OHSU.

We may release your information to others involved in conducting or overseeing research, including:

- The Office for Human Research Protections, a federal agency that oversees research involving humans

We will not release information about you to others not listed above, unless required or permitted by law. We will not use your name or your identity for publication or publicity purposes.

When we send information outside of OHSU, it may no longer be protected under federal or Oregon law. In this case, your information could be used and re-released without your permission.

Data from this study may be shared with other investigators for future research studies. All identifying information about you will be removed from the data before they are released to any other investigators.

We may continue to use and disclose your information as described above indefinitely.

Under Oregon Law, suspected elder abuse must be reported to appropriate authorities.

COMMERCIAL DEVELOPMENT:

Information about you or obtained from you in this research may be used for commercial purposes, such as making a discovery that could be patented or licensed to a company. There are no plans to pay you if this happens. You will not have any property rights or ownership or financial interest in or arising from products or data that may result from your participation in this study. Further, you will have no responsibility or liability for any use that may be made of your samples or information.

COSTS:

There will be no cost to you or your insurance company to participate in this study.

LIABILITY:

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact the study Principal Investigator, **Karen S. Lyons**, PhD, at (503) 494-3975**.**

You have not waived your legal rights by signing this form. If you are harmed by the study procedures, you will be treated. Oregon Health & Science University does not offer to pay for the cost of the treatment. Any claim you make against Oregon Health & Science University may be limited by the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you have questions on this subject, please call the OHSU Research Integrity Office at (503) 494-7887.

PARTICIPATION:

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You have the right to quit at any time if you join the study and later change your mind. This includes the right to withdraw your authorization to use and disclose your health information. You can choose to withdraw from the optional part of this study (data repository) without withdrawing from the whole study. If you choose not to join any or all parts of this study, or if you withdraw early from any or all parts of the study, there will be no penalty or loss of benefits to which you are otherwise entitled. This includes being able to receive health care services or insurance coverage for services. Talk to the investigator if you want to withdraw from the whole study or the optional part of the study.

If you no longer want your health information to be used and disclosed as described in this form, you must send a written request or email stating that you are revoking your authorization to:

Karen S. Lyons, PhD
Oregon Health and Science University School of Nursing
Mail Code: SN-ORD
3455 SW US Veterans Hospital Rd.
Portland, OR 97239-2941
email: lyonsk@ohsu.edu

Your request will be effective as of the date we receive it. However, health information collected before your request is received may continue to be used and disclosed to the extent that we have already acted based on your authorization.

You may be removed from the study if: the Principal Investigator stops the study, or at the discretion of the Principal Investigator.

We may give you new information during the course of this research study that might change the way you feel about being in the study.

SIGNATURES:

OPTIONAL PORTION OF STUDY

The optional portion of this study (data repository) is described in detail throughout this consent form and listed here as a summary. Please read the option below and place your initials next to it if you choose to participate. You can still participate in the main part of the study even if you choose not to participate in this optional part.

_____ I give my consent for my survey information to be stored in a repository and used for future research studies.

Your signature below indicates that you have read this entire form and that you agree to be in this study.

We will give you a copy of this signed form.

Subject Printed Name	Subject Signature	Date
Person Obtaining Consent Printed Name	Person Obtaining Consent Signature	Date