Operationalizing Person-Centered Caregiving Interactions in Dementia Care

by

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Abstract

Title: Operationalizing Person-Centered Caregiving Interactions in Dementia Care

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To address the limited understanding of person-centered care as it occurs at the level of hands-on care, videotaped interactions between certified nursing assistant caregivers and people with dementia during morning care were examined to establish those interactions that were uniquely person-centered. Following observation and description of both verbal and nonverbal interaction aspects of video-recorded episodes of morning care, qualitative description analysis methods were used to identify those interactions which were uniquely person-centered. After coding and analyzing six episodes, five interaction categories were identified from 116 caregiver-specific codes. These were 1) Seeking Guidance, 2) Validating Satisfaction, 3) Clarifying Ambiguity, 4) Negotiating Resistance, and 5) Adjusting Care. Each were determined to be necessary in person-centered caregiving based on the critical attributes of person-centered care discussed in the literature. Additionally, eight nonverbal principles of interaction, labeled Respecting Individuality, were identified. These principles provide a contextual foundation for the delivery of person-centered care. The results of this theory-building study are depicted in a conceptual model representing findings that are both clinically and theoretically meaningful to the practice and understanding of person-centered care during caregiving for the person with dementia.

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Operationalizing Person Centered Caregiving Interaction in Dementia Care

CHAPTER I: INTRODUCTION

Statement of the Problem

Forty-six percent of Americans who reach the age of 65 will require nursing home care at some point in their lives (Spillman & Lubitz, 2002). Older adults represent the fastest growing segment of the United States population, with an expected burgeoning of numbers by 2030, when 68 million Americans will have reached the age of 65 or older (Centers for Disease Control, 2005), doubling the current number of those in this age group who spend time in a nursing home by 2020 (Spillman & Lubitz) . The most recent statistics reveal that close to 6.5% of older adults over the age of 75 reside in nursing homes; the numbers increase dramatically with age, with 24.6% of those over the age of 85 living in a nursing home (National Center for Health Statistics, 2004). Current estimates suggest that 5.3 million Americans currently live with a diagnosis of Alzheimer’s disease (Alzheimer’s Association, 2010). As older adults live longer, the prevalence of cognitive impairment increases, with latest projections suggesting that by 2030, 7.7 million may be diagnosed with the disease, a number greater than the population of 140 of the 236 United Nations countries (Mikulski, 2007). As a result, the proportion of nursing home residents with dementia continues to accelerate, with some estimates as high as 74% (McDonald & Cooper, 2007). The nursing care needs of this rapidly growing population are critical now and will be more so in the years ahead.

Ongoing concerns for the quality of nursing home care have resulted in calls by the Institute of Medicine to improve health care by addressing the processes of care that promote effective and person-centered care (Wunderlich & Kohler, 2001). Person-centered care is health care that emphasizes the individual needs, priorities, and preferences of patients over those of health care team members or institutions (Gerteis, Edgman-Levitan, Daley & Delbanco, 2002; Laine, & Davidoff, 1996). In the past decade, there has been a surge of interest in person-centered care as a means of improving the care environment in nursing homes. Advocacy organizations such as the Pioneer Network and the Quality Initiative Organization of the Centers for Medicare and Medicaid Services have adopted person-centered ideals to approach quality of care concerns and are promoting the implementation of person-centered principles in nursing homes across the United States (Bowman & Schoeneman, 2006; Centers for Medicare and Medicaid Services, 2005; Fagan, 2003; Rader & Tornquist, 1995; Rantz & Flesner, 2004). Person centered models of care have been of particular interest to researchers, clinicians, and advocates working with persons with dementia because recent research and anecdotal reports suggest that person-centered strategies provide an effective approach to addressing behavioral issues in this population (Beck et al., 2002; Kitwood, 1997; Rader & Tornquist, 1995; Ryden & Feldt, 1992; Sloane et al, 2004; Talerico et al, 2006; Sabat, 2001).

The need for the development and testing of effective models of care for persons with dementia in nursing homes is clear. Increasingly, experts in the field are calling for evidence-based, effective, and innovative models that address the need for improvement in nursing home care for both residents and direct care staff (Casper & O’Rourke, 2008; Cherry et al., 2008; Harrison, Son, Kim, & Whall, 2007; Kane, 2001; Kitwood, 1997; Lustbader, 2001; Noelker & Harel, 2001; Rantz & Flesner, 2004; Stone et al., 2002; Tellis-Nayak, 2008; Weiner & Ronch, 2003; Wunderlich & Kohler, 2001). Patients, families, health care providers, payers, and consumer advocates alike agree that patient care in nursing homes should be different; it should reflect the individual preferences and needs of each unique person rather than serving the needs and schedules of the health care team members or institutions. Yet the predominant mode of providing nursing home care is an institutionally-driven model that cares for residents with a ‘one-size fits all’ approach (Talerico, O’Brien, & Swafford, 2003). A model of person-centered care is one that has been promoted but not sufficiently articulated or tested.

Research on person-centered care that addresses the interaction between the person with dementia and the certified nursing assistant [CNA] caregiver is particularly important because of the significant difficulties nursing home direct-care staff, primarily CNAs, experience when caring for persons with dementia (Beck et al., 2002; Everitt et al., 1991; Volicer, Bass, & Luther, 2007; Whall et al., 1992). Known for being a challenging patient population for caregivers, persons with dementia frequently exhibit aggressive and agitated behavioral symptoms. These distressing behavioral symptoms increase dramatically during assistance with activities of daily living [ADLs] (Beck, Rossby, & Baldwin, 1991; Burgener, Backas, Murray, Dunahee, & Tossey, 1998; Hoeffer et al., 1997; Kovach & Meyer-Arnold, 1997; Sloane et al., 1995; Ryden, Bossenmaier, & McLachan, 1991), which constitutes the vast majority of the care given to persons with dementia. The interaction that occurs during assistance with ADLs also serves as the primary source of human interaction for the person with dementia. The typical nursing home patient with dementia spends up to 60% of his/her day alone, with no additional substantial interaction from others (Norbergh, Asplund, Rassmussen, Hordahl, & Sandman, 2001). Thus, the caregiving period associated with assistance with

ADLs is a critical point for effective models of care that can both ameliorate behavioral distress and enhance caregiving interactions.

Research on person-centered care that addresses the interactions within the care dyad (the CNA caregiver and the person with dementia) is limited by a lack of identification of the specific behaviors and both verbal and nonverbal communication that make up these interactions during assistance with ADLs. This gap in knowledge contributes to poor conceptual distinctions and a resulting lack of instruments to measure person-centered interactions within the care dyad. Delineating the interactions within this care dyad and identifying those that are uniquely person-centered are fundamental steps in gaining conceptual clarity about person-centered strategies as well as in measuring this important construct.

The current conceptualization of person-centered care is limited in at least two ways: 1) concepts associated with person-centered approaches have been deductively derived and remain at a high-level of abstraction, making operationalization difficult for intervention studies, and 2) the majority of studies implementing person-centered care do so at a system level and have not specifically addressed the crucial interactions occurring within the care dyad during assistance with ADLs. This study addressed these limitations through detailed inductive description of person-centered and non person-centered interactions using videotapes of CNA caregivers providing morning care to persons with dementia.

Study Aim

The purpose of this study was to contribute to concept development of person-centered caregiving interactions between CNA caregivers and persons with dementia during assistance with morning-care ADLs. This purpose was accomplished through detailed description and analysis of the hands-on activities as well as verbal and non-verbal communication that make up caregiving interactions. The primary aim of the study was to develop conceptual definitions of person-centered interactions that occur within the care dyad during assistance with ADLs by analyzing videotapes of morning care from a previously-conducted study.

Significance to Nursing

The study has considerable significance to both nursing and all health care professions that work with older adults with dementia. Inductively-based conceptual understandings of person-centered care that focus on the level of direct caregiving provide an essential contribution to the ongoing theory development of person-centered care and are an essential first step in the development of a precise and sensitive measure of person-centered care. Further, delineating the defining characteristics of caregiving interactions that are person-centered contribute to the development of targeted intervention strategies for caregivers that are crucial to the improvement of the overall quality of nursing care for people with dementia, in nursing homes and potentially in all settings where direct caregiving occurs.

CHAPTER II: REVIEW OF THE LITERATURE

This chapter presents a review of the literature and an assessment of the conceptual maturity of person-centered care provided to people with dementia in the nursing home setting. Literature relating to person centered care and caregiving interactions is the focus of the review. The Integrated Approach to Concept Development (Meleis, 2007) and strategies espoused by Morse (2004) guided the review of the literature and resulting beginning conceptual framework for this study.

Person-Centered Care as a Philosophy of Care

In this section the various terms used throughout the literature to reference person-centered approaches to health care are introduced. Additionally, the section includes a discussion of the general consensus surrounding attributes associated with this philosophy of care and the underlying assumptions inherent in each attribute. The section concludes with an evaluation of the conceptual maturity of person-centered care, discussing gaps in extant knowledge.

Terms Used in the Literature to Reflect Similar Philosophies

Patient-centered care, patient-focused care, person-centered care, consumer-centered care, client-centered care, resident-centered care, person-directed care, and individualized care are all terms frequently used in health care literature referring to approaches of care that focus on the priorities of the patient. The terms vary, yet share a loose consensus of principles and similar basic concepts, which will be the focus of this review. The use of multiple terms to reference the same or similar philosophies of care suggests an overall lack of conceptual precision and clarity, complicating the development of consistent thought regarding defining attributes and characteristics

(Morse, 2004). Conceptual clarity is essential for the development of nursing science with the precise selection of terms fundamental to the process of conceptual development (Waltz, Strickland, & Lenz, 2005). The term “person-centered care” was originally selected for use throughout the study because it reflected a focus on the uniqueness of a person beyond who they are as a purchaser of health care or who they are in a sick role (Talerico, O’Brien, & Swafford, 2003), in contrast to terms such as resident-centered care, client-centered care, or patient-focused care which imply a consumer orientation. Additionally, person-centered care was in common usage at the time of the study’s origin. Since that time, there has been a move away from the term person-centered care to that of person-directed care (e.g., Pioneer Network, Oregon Geriatrics Society, Mather LifeWays Institute on Aging, Centers for Medicare and Medicaid) with evidence of the use of this term entering the research literature as well (White, Newton-Curtis, & Lyons, 2008). For purposes of this study, “person-centered care” will be used to refer to care that emphasizes the individual needs, priorities, and preferences of patients over those of health care team members or institutions (Gerteis, Edgman-Levitan, Daley & Delbanco, 2002; Laine, & Davidoff, 1996).

Gerontological nursing research and literature addressing approaches to care that focus on the priorities of the person receiving care most often refer to a phenomenon of varying levels of abstraction and scope, presenting the construct as a macro-level concept, a global theme, or a philosophy of care. Virtually all phenomena can be considered as consisting of “hierarchically arranged levels, with larger and more inclusive or more molar concepts occupying each higher level, and smaller and more detailed or more molecular concepts occupying each lower level” (Bakeman & Gottman, 1997, p. 24). A primary aim of the proposed study is to develop the concept of person-centered care at the more molecular level, as it occurs within the interaction between the care dyad. However, development of lower level concepts is largely dependent on the degree of clarity and maturation of the concept at the molar level, as molar level concepts provide ‘scaffolding’ from which molecular level concepts are detailed and explicated (Morse & Mitcham, 2002). Contributing to both the molar and molecular level conceptualization of person-centered care is critical to the practical implementation of this approach to nursing care.

Current Conceptualizations

Through the conceptual development work of scholars such as Claire Bamford, Dawn Brooker, Lois Evans, Tom Kitwood, Astrid Norberg, and Marilyn Rantz, some consistency of thought has arisen as to the critical attributes of person-centered care. The resulting loose consensus of principles--knowing the person, relationship, supportive environment, autonomy and choice, therapeutic agency of the caregiver, and personhood--has guided much of the recent person-centered care inquiry. Each of these attributes is reviewed below.

Knowing the person. The critical attribute of knowing the person refers to aspects of care that respect the uniqueness of the individual (Bamford et al., 2008; Boettcher, Kemeny, DeShon, & Stevens, 2004; Brooker, 2007; Evans, 1996; Finnema, Droes, & Van Tilburg, 2000; Happ, Williams, Strumpf, & Burger, 1996; Kitwood, 1997; Rader & Tornquist, 1995; Rantz & Flesner, 2004; Talerico, O’Brien & Swafford, 2003; White, 2007). Underlying this core value within person-centered care is the belief that disease-related or age-related changes have no bearing on the uniqueness or humanity of the person, a value congruent with nursing caring theories, such as put forth by Jean Watson. At the same time, information about the affect of age-related changes or disease processes on any given individual is necessary for appropriate and effective care. A critical role of any caregiver is to maintain and support the uniqueness, dignity and humanity of the individual (Watson, as cited in Fitzpatrick & Whall, 2005). The essence of these ideals is captured in the phrase <u>knowing the person</u>.

Each individual's uniqueness is promoted through knowledge of the person that incorporates an understanding of a person's usual routine, important family and social relationships, premorbid personality, dementia-related disabilities, reactions to caregiving situations, medical/nursing care issues, and a person's work history and leisure interests into nursing care (Happ, Williams, Strumpf, & Burger, 1996, Harvath, 1990). Evans (1996) defines this core value as "striving to understand an event as it has meaning in the life of the other. It includes avoiding assumptions, centering on the one being cared for, assessing thoroughly, seeking cues, and engaging the self of both" (p. 19). Based on this knowledge, which is communicated formally via nursing care plans, an individual's needs and preferences are incorporated into care so that current ways of living are congruent with past patterns of living (Talerico, O'Brien & Swafford, 2003).

Relationship. Relationship, the second attribute of person-centered care is generally defined as consistent, trusting, and empathic social interactions that contribute to a positive social environment (Bamford et al., 2008; Boettcher, Kemeny, DeShon, & Stevens, 2004; Brooker, 2004, 2007; Edvardsson et al., 2008; Evans, 1996; Finnema, Droes, & Van Tilburg, 2000; Happ, Williams, Strumpf, & Burger, 1996; Kilhgren, Hallgren, Norberg, Karlsson, 1994; Rader & Tornquist, 1995; Talerico, O'Brien &

Swafford, 2003; White, 2007; Williams, 2001). Relationship, as a core aspect of person-centered care, is promoted through consistent and recurring caregiving for the same individual that creates the opportunity for development of both the knowledge and the interpersonal exchanges that enhance care. This core value incorporates the therapeutic use of self (Athlin & Norberg, 1999; Evans, 1996), a major component of nursing interaction theorists, particularly Paterson and Zderad (as cited in Meleis, 2007) and Travelbee (as cited in Meleis) who promote a belief in the ability of the caregiver to offer more than a mechanistic act of care that is task-oriented by developing a relationship with the person being cared for, shifting toward caring acts that are humanistic in nature.

An additional assumption underlying the relationship attribute is that caregiving acts involve a degree of reciprocity. Relationship entails the participation of two people; yet because of disease-related deficits in persons with dementia, equal participation may not be possible (Athlin & Norberg, 1999). However, the belief within person-centered care ideals is that some degree of participation remains possible, even for the person with dementia, as long as there is consciousness (Kitwood, 1997; Williams, 2001). This assumption is supported by the nursing caring theorist, Jean Watson, who promotes a process of caring relationship that benefits both the care recipient and the caregiver (as cited in Fitzpatrick & Whall, 2005).

Other attributes of person-centered care. Other attributes are referred to in the literature, either directly or inferred based on study outcome measures, but with less overall consensus. A discussion of these four attributes follows.

A number of authors propose that care is not truly person-centered unless the physical, social, organizational, and emotional environment is supportive in a way that adjusts to meet the individual's needs and preferences; this attribute has been labeled supportive environment (Bamford et al., 2008; Hoeffer et al., 2006; Kitwood, 1997; Talerico, O'Brien & Swafford, 2003; White, 2007). Valuing the vital role of the caregiver to monitor, regulate, and change both the immediate and the broader environment as critical to the person's experience is a core concept in nursing, dating back to Florence Nightengale's writings in the 1860's. While there is not full consensus about the inclusion of the attribute of supportive environment, it is nonetheless believed to be important to the conceptualization of the construct by the investigator of the current study. Care cannot be truly person-centered unless aspects of the environment are supportive in ways that meet the individual's needs and preferences. To be supportive of and accommodate one's preferences, aspects of the nursing home environment need to allow for freedom of choice and maximum control over one's environment, including risk taking (Hoeffer et al., 2006; Kitwood, 1997; Swafford, 2003; Talerico, O'Brien & Swafford, 2003; White, 2007).

The importance of the attribute of supportive environment is highlighted in Kayser-Jones' (1989) theoretical framework of person-environment interaction in long-term care, in which she suggests that when the physical characteristics, organizational climate, and psychosocial milieu 'fit' with the personal needs of the person residing in long-term care, there will be a high level of well-being or adaptation. The context of care delivery influences the care-recipient's experience of care. This context of care includes both the immediate environment (e.g., sufficient supplies at hand, interruption-free caregiving, and noise levels) and the broader system-level environment (e.g., job satisfaction, available information necessary for care, positive communication with co-workers and supervisors).

Autonomy and choice is also viewed as an essential attribute of person-centered care (Bamford et al., 2008; Happ, Williams, Strumpf, & Burger, 1996; Kane, 2003; Kilhgren, Hallgren, Norberg, & Karlsson,1994; Sharpp, 2009; Talerico, O'Brien, & Swafford, 2003; White, Newton-Curtis, & Lyons, 2008). This attribute is defined as an approach that encourages residents to guide care decisions in all aspects that he/she is capable (Happ et al., 1996; Kane, 2003; White et al., 2008). White and colleagues (2008) suggest that "in a person directed environment, the assumption is that independence enhances competence and that care must be supportive of personal agency. Emphasis is on empowering residents, even those with cognitive impairments, to make their own decisions about their care, schedules, and activities" (p. 115). The concept additionally highlights maintaining normal routines and the right to take risks (Cohen-Mansfield & Bester, 2006; Rader & Tornquist, 1995; Talerico, et al., 2003). One might argue that it is through understanding choice that the attribute of knowing the person, with the underlying values of promoting the uniqueness of each individual, is carried out. Viewed in this way, choice may reflect a concept within person-centered care that is more process based, beginning to capture the 'doing' of person-centered care rather than a core attribute or value of the philosophy of person-centered care. Additionally, it is viewed as a component of supportive environment, captured in the aspect of the definition of this attribute related to the facilitation of choice, risk taking, and supporting the resident's control over his/her environment.

A number of authors suggest that care is not person-centered without a caregiver acting as a therapeutic agent (Athlin & Norberg, 1997; Bamford et al., 2008; Boettcher, Kemeny, DeShon, & Stevens, 2004; Kitwood, 1997). The overt inclusion of the caregiver as essential to person-centered care begins to move the conceptualization of person-centered care from the molar to the molecular. The molar-level values of person-centered care apply not only to the person receiving care or the person providing care, but to the larger system in which caregiving occurs, such that all people, from the administrator, the housekeeping staff, the kitchen staff, the book-keeper, the nurse manager, the floor nurse, to the CNA caregiver, play an important role in contributing to a system that has integrated these ideals to promote person-centered care (Kitwood 1997; Williams, 2001; Lustbader, 2001).

An inclusive understanding of the application of the core attributes of person-centered care as a philosophy of care, or a molar-level construct, preclude the need to identify one particular member of the care team as more essential than another. However, the identification of the CNA caregiver as crucial to the molecular level application of person-centered care may have more relevance. Certainly the person providing care, be it the CNA caregiver or a nurse, or a family member, is in a direct position to either implement or not implement person-centered care practices.

Finally, the attribute of personhood, refers to an underlying attitude that promotes the value and dignity of each individual as a human being, focusing on the present strengths and abilities of the person (Finnema, Droes, & Van Tilberg, 2000; Kitwood, 1997; Nolan, Davies, Brown, Keady & Nolan, 2004; White, Newton-Curtis, & Lyons, 2008). More than other identified potential attributes, the inclusion of personhood blurs conceptually with the ideals and values associated with the attribute of knowing the person, making clear the need for concept clarification at this more abstract level. Questions are raised, such as, 'is the attribute of personhood an overarching, fundamental attribute that is then put into practice by the lower, but still molar-level concept of knowing the person?' or 'are the two concepts distinct, but at the same conceptual level?' These questions await clarification through detailed concept analyses and resulting theory building as well as through consensus among researchers, clinical experts, and recipients of care.

Evaluation of Conceptual Maturity of Person-Centered Care and Need for Development

The core attributes of person-centered care as derived from a review of the literature provide a beginning understanding of person-centered care as a philosophical approach to nursing home care. However, the concept is in need of further development, refinement, and clarification. Following Morse and colleagues' (1996) criteria for concept evaluation, the lack of agreement and the lack of fully articulated and distinct attributes suggest that the concept has not reached maturity. Additionally, the lack of clearly demarcated boundaries of the concept, "what is and what is not part of the concept"(Morse, Mitcham, Hupcey, & Tason, 1996, p. 388), gives further evidence of the fact that person-centered care remains only a moderately developed concept. This study used inductive methods to address this gap and contribute to refinement of the conceptualization of person-centered care and development of molecular level concepts (Morse, et al., 1996).

Person-Centered Care and Interactions between Caregiver and Person with Dementia

This section provides an overview of person-centered care as it is conceptualized at the level of care-dyad (made up of the CNA caregiver and the person with dementia) interaction. The relevance of the interaction within this dyad is discussed along with underlying assumptions about the interactions that occur in the context of care delivery. To further address the context of caregiving, a discussion of the concept of immediate and enduring needs follows. The section is closed with a review of the extant literature regarding current conceptualizations of person-centered care during the interaction within the care-dyad during assistance with ADLs.

Person-centered care has primarily been studied and discussed in the literature as a philosophy of care. Because of this, there is an even greater lack of conceptual clarity surrounding the lower level, or more molecular concepts that are particular to the phenomenon of person-centered care, such as those that occur during the interaction between the CNA caregiver and the person with dementia.

Only one researcher was found that sought to delineate the attributes of person centered care at the caregiving interaction level. In her ethnographic dissertation research, Sharpp (2009) identified four qualities unique to person-centered interactions. These are a) advocacy, b) affection, c) allowing autonomy, and d) attachment. Each of these qualities has its origins in the broader corresponding attributes, knowing the person, personhood, autonomy, and relationship. They are a helpful contribution to the beginning discussion of interaction characteristics that are exclusive to person-centered caregiving.

The Importance of Interaction between Caregiver and Person with Dementia

Interactions between the CNA caregiver and the person with dementia are fundamental to the provision of person-centered care. Interactions are the integrated exchanges of verbal and nonverbal communication between two parties (Athlin & Norberg, 1987; Sundeen, Stuart, Rankin, & Cohen, 1998), and include the provision of care. The role of the caregiver is particularly salient when interactions involve a person with dementia who, by nature of the losses in memory, executive function and communication abilities, is at risk of being objectified or dehumanized during care, often because expected social interaction patterns no longer apply (Athlin & Norberg, 1987; Kihlgren, Hallgren, Norberg, & Karlsson, 1994; Kitwood, 1990). To minimize this risk, the caregiver has the responsibility for the effectiveness of interactions based on their actions and responses (Athlin & Norberg, 1987; Eckman, 1991; Kilhgren et al., 1994).

Dementia-related cognitive changes result in significant communication deficits, potentially rendering the person with dementia unable to effectively verbalize needs, preferences, or goals. As a result, communication is often expressed nonverbally; these nonverbal expressions are thought to be meaningful and potentially useful for guiding the delivery of care, as proposed in the Need-Driven Dementia-Compromised Behaviors Model (Algase et al., 1996). In this model, all behaviors, particularly those that are perceived by caregivers as problematic (i.e. kicking, grabbing, yelling, or other forms of distress) are viewed as representing unmet needs that then serve as the basis for evaluation and direction of care in response to the need.

The assumption that all behavior has meaning and is useful for guiding caregiving responses was critical for the development of the present study. Underlying this core assumption is the belief that the person with dementia retains the capacity for communication through the use of verbalizations, vocalizations, facial expressions, and physical actions. Due to disease processes, communication ability is altered, requiring unique skills by the caregiver, who must be attentive to the needs and preferences that are being communicated nonverbally during caregiving interactions (Edberg, Sandgren, & Hallberg, 1995; Kolanowski, 2000; Whall & Kolanowski, 2004).

Enduring vs. immediate needs, preferences, and goals. In this study, a distinction was made between those needs, preferences, and goals that are enduring, and those that are more immediate and dynamic. Enduring needs, preferences, and goals, also termed 'background factors' by Algase et al. (1996), are associated with medical and functional needs, life history, and personality, and have often been made known prior to the onset of dementia. These needs and preferences are those that can be addressed through thorough assessment and care planning; following the care plan then serves as the method to meet the person's needs and preferences, thereby delivering a degree of person-centered care.

Needs, preferences, and goals that are more dynamic, such as those encountered during immediate episodes of caregiving are related to one's mood, interpretation of events, fatigue, acute illness, changes associated with subtle cognitive deterioration, or may represent variations that occur in normal human behavior. These needs would be included under the umbrella term, 'proximal factors', in the Need-Driven Dementia-Compromised Behavior Model (Algase et al, 1996). These needs may change from caregiving episode to caregiving episode, which make them difficult to address through care planning. For example, a person with dementia may decide differently each day if given the simple choice of whether to wear lipstick. Further, the variations of each day are often expressed in one's readiness to get out of bed and prepare for the day. Person-centered care, at the most molecular level, seeks to meet these more dynamic needs and preferences as well as those addressed through care planning. Addressing both dimensions is critical to person-centered care delivery. However, the current study focused on the more immediate and dynamic needs and preferences within the caregiving episode because of the significant gap in understanding in this area.

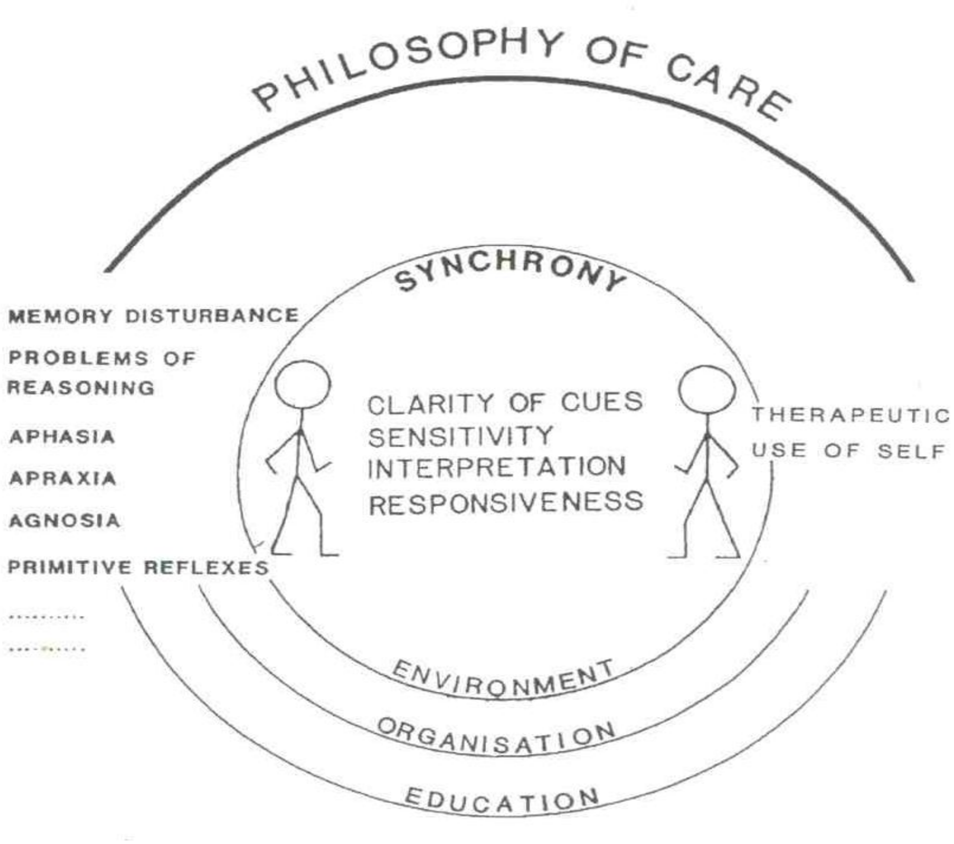
Conceptualizations of Person-Centered Care within Care-dyad Interactions

Caregiving interaction between caregivers and persons with dementia has been studied in some detail, with investigators exploring the implementation of various models of caregiving (e.g., an abilities-focused program by Wells, Dawson, Sidani, Craig, and Pringle, 2000; the preserved implicit memory model by Harrison, Son, Kim, and Whall, 2007; and a stress-adaptation model by Corbeil, Quayhagen and Quayhagen, 1999) or the cognitive process of decision making during caregiving (Anderson et al., 2005; Fisher & Wallhagen, 2008; Janes, Sidani, Cott, & Rappolt, 2008; and Skovdahl, Kihlgren, & Kihlgren, 2004). Several other investigators have directly explored the relationship between caregiver interaction style and resident behavior (Burgener, Jirovec, Murrell, & Barton, 1992; Edberg, Sandgren, & Hallberg, 1995; Gotell, Brown, & Ekman, 2009). However, none addressed person-centered caregiving interactions.

A few researchers have directly conceptualized and/or investigated person-centered caregiving interactions. (Adelson et al., 1982; Athlin & Norberg, 1987; Boettcher, Kemeny, DeShon, & Stevens, 2004; Hoeffer et al., 2006; Kitwood, 1997). The work of these authors informed the literature-based provisional framework used in this study. These conceptualizations will be discussed individually, concluding with a summary of the provisional labels that were used during data analysis for this study. Of note, Sharpp's (2009) conceptualization was unavailable during analysis of the current study.

Model of interaction during feeding persons with severe dementia. Athlin and Norberg (1987) made a substantial contribution to the conceptual development of person-centered interactions within the care dyad in their 'model of interaction during feeding persons with severe dementia' (Figure 1). The strength and uniqueness of this model lies in the introduction of four interaction variables: 1) clarity of cues, 2) sensitivity, 3) interpretation, and 4) responsiveness. Each of these variables is suggested to enhance or detract from the effectiveness of the feeding interaction with the person with dementia; greater effectiveness is possible when the caregiver acts in a compensatory manner, using self in a therapeutic way.

Figure 1. Model of Interaction During Feeding Persons With Severe Dementia



While the focus of the authors' model was conceptualizing interactions during feeding a person with dementia, the model has merit in the theoretical conceptualization of the current study. However, the investigator considered the variables 'clarity of cues', 'sensitivity', and 'interpretation' as antecedents to the actual delivery of a unique and discreet person-centered interaction. As such, these characteristics of interaction are not the essence of person-centered caregiving independently, they are aspects of the participants which either enhance or detract from the ability of the care dyad to be effective in the exchange, which is then reflected in the responsiveness of both members of the care dyad. Viewed in this way, the expected outcome of the study at hand was to describe the interactions that are part of 'responsiveness', believing that the verbal and nonverbal content making up the caregiver's responses within an interaction were the core of person-centered care at this level of analysis. The conclusion was that 'responsiveness' may be a critical attribute of person-centered care interactions. This supported clinical observations and evidence-based recommendations that suggest a person with dementia experiences less distress when a CNA caregiver is respectful in their responses to distressed verbal and nonverbal behavior rather than ignoring or minimizing the behavior (Burgener, Bakas, Murray, Dunahee, & Tossey, 1998; Chalmers, 2000, Hoeffer et al., 2006; Kovach & Meyer-Arnold, 1997). Thus the variable 'responsiveness' was included as a provisional label as analysis reached the determination of person-centeredness.

While Athlin and Norberg's (1987) model provides a substantial contribution to the conceptualization of the interactions that occur during caregiving activities for persons with dementia, there are also limitations. The authors present a perspective that the person with dementia is only capable of bringing deficits and loss to the interaction. Because of cognitive losses, behaviors from the person with dementia are conceptualized as 'chaotic' and meaningless; according to these authors, apparent signs of communication such as different frequencies of eye blinking are only primitive reflexes and serve no communication purpose. This deficit-oriented perspective risks perpetuating depersonalizing or objectifying interactions during care, and is not consistent with the underlying assumptions within the proposed study.

Positive-person work. Kitwood (1997) made an important contribution to the conceptualization of lower-level concepts associated with the delivery of person-centered care through the identification of ten types of person-centered interactions termed

Positive Person Work; these are provided in Table 1. Many of the terms have substantial clinical validity, but their development lacks a documented research base and has yet to be verified or validated. There is also considerable ambiguity about the application of these terms to the interactions that occur during assistance with ADLs as opposed to interactions that occur in the course of social or general conversational engagement.

Kitwood (1997) readily acknowledged the need for a full elaboration of these terms and called for research to provide a much higher level of detail regarding characteristics of person-centered interactions. For the purposes of the current study, several of the terms, namely ‘recognition,’ ‘negotiation,’ ‘collaboration,’ and ‘facilitation’ appear to have relevance to interactions that occur during assistance with ADLs. Other terms, such as ‘celebration’ and ‘holding’ are more abstract emotional experiences that are difficult to measure or validate using observational methods. Still other terms, such as ‘relaxation,’ lack a sufficient definition to provide a full evaluation of the fit of the term into person-centered interactions. In this study, the investigator sought to verify and elaborate on these terms, specifically attending to ‘recognition,’ ‘facilitation,’ ‘negotiation,’ and ‘collaboration,’ which served as a beginning provisional category list for observed interactions in the study. However, congruent with inductive inquiry, it was understood that if the data did not support these provisional categories, modifications based on emerging findings would be offered (Morse, 2002).

Table 1. Positive Person Work (Kitwood, 1997, p. 90-92).

Interaction Type	Definition
Recognition	Acknowledgement as a person, known by name, affirmed in his/her own uniqueness. May be achieved in a simple act of greeting, or in careful listening over a longer period of time; never purely verbal, may not involve words at all; direct eye contact can convey recognition.
Negotiation	Consulting the person about their preferences, desires and

Interaction Type	Definition
	needs, rather than being conformed to others' assumptions; Skilled negotiation takes into account the anxieties and insecurities of the person, and the slower rate at which they handle info; gives some degree of control back to the patient
Collaboration	Alignment on a shared task with a definite aim in view; task is not done to a person, but is a process in which their own initiative and abilities are involved
Play	No goal that lies outside the activity itself. An exercise in spontaneity and self-expression
Timalation	Forms of interaction in which the prime modality is sensuous or sensual, such as aromatherapy or massage; provides contact, reassurance, and pleasure while making very few demands.
Celebration	Ambiance is expansive and convivial; any moment in which life is experienced as intrinsically joyful; division between caregiver and patient come nearest to vanishing completely, all are taken up into a similar mood; selfhood has expanded, boundaries of ego are diffuse
Relaxation	Of all the forms of interaction, this has the lowest level of intensity and slowest pace
Validation	Acknowledging the reality of a person's emotions and feelings and giving a response on the feeling level.
Holding	Psychological metaphor; providing a safe psychological space where hidden trauma, conflict or extreme vulnerability can be exposed; when the holding is secure, a person can know that devastating terror or overwhelming grief will pass and not cause the psyche to disintegrate;
Facilitation	Enabling a person to do what otherwise he or she would not be able to do by providing those parts of the action (and only those) that are missing. Merges with collaboration. The task of facilitation is to enable interaction to get started, to amplify it and to help the person gradually to fill it out with meaning. When this is done well, there is a great sensitivity to the possible meanings in a person's movements, and interaction proceeds at a speed that is slow enough to allow meaning to develop.
Creation	The person with dementia spontaneously offers something to the social setting, from his or her stock of ability and social skill. An example would be the initiation of a song or dance with an invitation to others to join in.
Giving	A form of interaction that approximates the I-Thou mode. The PWD expresses concern, affection, or gratitude; makes an offer of help, or presents a gift. There is sometimes a great sensitivity to the moods and feelings of caregivers, and a warmth and sincerity.

Health professional-geriatric patient interaction behavior rating code. Adelson and colleagues (1982) also make an important contribution to the conceptual development of person-centered care interactions through their deductively derived Health Professional-Geriatric Patient Interaction Behavior Rating Code, a measure of ‘positive interaction’ skills of health professionals.

Although the behavioral categories are not conceptualized as person-centered, they have great relevance for person-centered interactions. The specific behaviors and their definitions are provided in Table 2.

Table 2: Health Professional-Geriatric Patient Interaction Behavior Rating Code

Behavior	Definition
Banter	Engages patient in conversation
Asks for feedback	Gives choices, develops options for the patient, asks if something hurts or how it feels
Gives procedural information	Warns patient of upcoming sensation, touch, taste or smell.
Compensates for disabilities	Adapts to patient’s impairment, for example, loss of hearing, sight or other physical disabilities
Social touches	Physical contact that is an expression of affection, comfort, reassurance, or concern, and not considered procedural
Attends to patient comfort	Expresses concern for the patient’s ease and is sensitive to the needs of the patient.
Appropriate smiling	Scored as “too little, adequate, or very good”
Pacing of procedure	Too fast, too slow, just right
Pacing of speech	Too fast, too slow, just right

In this scheme, several behavioral categories have significant face validity for person-centered care interactions, particularly ‘asks for feedback’ and the two ‘pacing’ categories. ‘Asking for feedback’ suggests a mode of soliciting the person’s preferences, needs, and goals and thus is conceptually consistent with the delivery of person-centered care. The categories of pacing of procedure and speech appear to be equally consistent with person-centered care interactions because within these categories, it is implied that the caregiver is responding to the person's cues to adjust the pace of activity or speech to meet the immediate needs of the caregiving situation. These three categories were added to the provisional list borrowed from Kitwood (1997) for the current study.

The remaining six categories from the measure were viewed more cautiously because they appear to represent characteristics of general positive interactions that one would expect with any high-quality care, and therefore are not likely to be unique to person-centered ways of caring. Those remaining categories were not included in the provisional category list.

Hoeffer and colleagues. In a randomized, controlled clinical trial of two methods of 'person-centered' bathing, Hoeffer and colleagues (2006) examined the extent to which CNA caregiver behavior changed after an education intervention by comparing the observed frequency of two pre-selected behaviors. <u>Gentleness</u> (uses calm voice, speaks respectfully, hurries through bath (reverse coded), and gently touches) and <u>verbal support</u> (praises resident, expresses concern or interest, speaks directly to resident, and prepares resident for task) were rated by blinded, trained coders viewing video recorded bathing episodes. The authors found that providing 'person-centered care', as reflected with these behavioral measures, during assistance with bathing resulted in decreases in agitation, aggression and discomfort. The authors conceptualized 'personalizing care', as the 1) accommodation of residents' needs and preferences and 2) alteration of the physical environment, each within the context of a positive relationship.

Similar to several of the categories included in the Health Professional-Geriatric Patient Interaction Behavior Rating Code (Adelson et al., 1982), the category labels of 'gentleness' and 'verbal support' in the person-centered bathing study are viewed to reflect behaviors and actions expected within good dementia care. Thus, 'gentleness' and 'verbal support' were not included as labels in the literature-based, provisional category list. For the current study, the descriptor for gentleness, 'hurries through bath', which was reversed coded, is useful, and is addressed by the 'pacing' label of the Health Professional-Geriatric Patient Interaction Behavior Rating Code. One critique of Hoeffer and colleagues' study (2006) was that the measured behaviors do not directly correspond to the authors' conceptualization of 'personalizing care'. In other words, there is no measure of accommodation by the caregiver nor is there a measure of whether an alteration of the physical environment occurred. Instead, the authors focused primarily on the 'positive relationship' aspect of their conceptualization.

On-the-job performance measures of person-centered care. Changes in caregiver 'on-the-job' behavior after a person-centered care staff development intervention were measured using a conceptualization of person-centered care as care that "respects individuality, maximizes independence, and maintains previously enjoyed activities" (Boettcher, Kemeny, DeShon, & Stevens, 2004, p.189). To measure caregiver behavior change, a rubric-type tool was developed reflecting this broad conceptualization (Table 3).

Table 3. On-the-job Performance Measures of Person-Centered Care

Component	Definition
Nonverbal initiation of PCC interactions	Uses nonverbal behaviors when initiating an interaction with a resident that demonstrates respect for the resident's individuality
Assistance with independence-oriented tasks	Uses both verbal and nonverbal behaviors that are designed to initiate residents' performance of tasks that may be completed independently once begun
Conversation	Uses verbal statements designed to enhance residents' feelings of belonging and self-worth and avoids using statements that dehumanize, disrespect, or threaten
Interacting using unique details	Uses residents' preferred name and refers to unique

Component	Definition
of resident’s lives	details of their lives when referring to them
Initiating lifestyle activities	Organizes lifestyle activities that meet resident’s individual needs
PCC interactions with family	Requests family member’s input about resident’s care, restates their feelings to convey understanding, and communicates with them as individuals
Responding to need driven behaviors	Uses strategies such as making reassuring statements to meet resident’s immediate needs

Careful evaluation of these seven components suggests a lack of conceptual precision and comprehensiveness. In relation to the current study, the components are broadly described and appear to reflect categories more abstract than expected from the study at hand. Two components, ‘interactions with family’ and ‘initiation of lifestyle activities’, lack face validity when applied to measurement of person-centered care during assistance with ADLs because family members would not be present and the assistance with ADL care does not allow for the promotion of lifestyle activities. In general, the other components are vaguely defined, leading to measurement challenges.

‘Responding to need driven behaviors’ and ‘interacting using unique details of resident’s lives’ were viewed by the investigator as potentially useful category labels. Delineation of the specific strategies that caregivers use in response to need-driven behaviors and careful description of the use of life details during the delivery of care were expected outcomes of the study, making these two categories relevant. Additionally, clarification of the non-verbal behaviors that demonstrate respect for the resident’s individuality referenced in the first component, or detailed descriptions of the verbal and non-verbal behaviors that encourage residents’ independence (referenced in the second component) would strengthen this developing tool, and were also expected outcomes of this study.

Provisional Labels

The body of literature on person-centered care at both molar and molecular levels provided a meaningful foundation for the current study and served as a provisional guide in analysis of the data (Table 4). The investigator examined and built on this literature based through a qualitative approach to concept development by defining person-centered caregiving interactions that occur during assistance with ADLs.

Table 4. Provisional labels for data analysis

Extant Source	Provisional Label
Model of Interaction During Feeding Persons With Severe Dementia (Athlin & Norberg, 1997)	Responsiveness
Positive Person Work (Kitwood, 1997)	Recognition Facilitation Negotiation Collaboration
Health professional-geriatric patient interaction behavior rating code (Adelson, Nasti, Sprafkin, Marinelli, Primavera, and Gorman, 1987)	Asking for feedback Pacing procedure Pacing speech
On-the-job performance measures of person-centered care (Boettcher, Kemeny, DeShon, & Stevens, 2004)	Responding to need driven behaviors Use of unique details of resident's lives Respecting individuality Encouraging independence

Conclusion

In evaluating the conceptual maturity of person-centered care, it is clear that considerable progress has been made in its conceptualization at a high-level of abstraction; current theoretical understandings contribute to broad, over-arching concepts encompassed by this philosophy of care. Through primarily deductive means, several attributes have been identified but minimally explored. As deductively derived, currently accepted person-centered care concepts require verification, and may require modification and refinement (Morse, 2002).

Significantly less research is published about molecular low-level concepts encompassed by the construct of person-centered care, such as those concepts associated with person-centered caregiving interactions during assistance with ADL care, despite the importance of care delivery interactions in implementing models of care. The lack of clearly delineated concepts associated with person-centered care provided rationale for the need for further concept development (Morse, Hupcey, Mitcham, & Lenz, 1996). Both the molar-level understandings and developing molecular-level conceptualizations can inform ongoing concept development by serving as ‘scaffolding’ for inductive investigation of internal attributes that will further our understanding (Morse, 2004). Thus, the purpose of this study was to identify and define caregiving interactions that are uniquely person-centered as they occur during morning care for people with dementia.

CHAPTER III

METHODS

Design

A naturalistic design with qualitative description methods was used to analyze videotaped episodes of morning care provided by CNA caregivers to persons with dementia in order to describe person-centered caregiving interactions during hands-on care. Drawing on the general tenets of naturalistic inquiry, qualitative description requires that the researcher study an event in its natural state (Lincoln & Guba, 1985). Qualitative description entails a low-inference summary of an event in which data are minimally transformed or interpreted, with results remaining close to the level of abstraction of the data (Morse, Mitcham, Hupcey, & Tason, 1996). Qualitative descriptive methods rely on data that richly reflects the phenomenon of interest, and can include both subjective reports, such as interviews, or observational data, such as videos, and/or examination of documents (Sandelowski, 2000). In this study, videotaped episodes of morning care served as the data source. For this study, all viewing, transcribing, memoing, and coding was done using Transana, a software program specifically designed for the qualitative analysis of large video files (Fassnacht, 2005).

Inductive, observational approaches to the development of descriptive knowledge are particularly important to advance nursing knowledge of clinical situations in which behavioral phenomenon are poorly understood (Warnock & Allen, 2003). Findings from qualitative descriptive work focus on patterned responses in the data and provide an informational, well-organized, comprehensive summary of details associated with the phenomenon of interest (Sandelowski & Barroso, 2003). The descriptions derived directly from the data as a result of this method are best suited to development of concepts considered low-level concepts (Morse, 2004), a primary goal of the study. This method therefore, enabled the investigator to achieve the study aim to describe the person-centered interactions between CNA caregivers and persons with dementia.

When the aim of qualitative inquiry is the development of concepts about which something is already theorized, Morse & Mitcham (2002) suggest that inductive work can be accomplished despite the investigator's awareness of a priori information. Through a 'neutral but questioning' position, an investigator can build on and move beyond what has been described previously (Morse, 2002). For the purposes of this study, the investigator expected some interactions would be identified as person-centered based on the beginning conceptual foundations as documented in the literature (Table 1). These provisional labels were used in later stages of data analysis.

Table 1. Provisional labels for data analysis

Extant Source	Provisional Label
Model of Interaction During Feeding Persons With Severe Dementia (Athlin & Norberg, 1997)	Responsiveness
Positive Person Work (Kitwood, 1997)	Recognition Facilitation Negotiation Collaboration
Health professional-geriatric patient interaction behavior rating code (Adelson, Nasti, Sprafkin, Marinelli, Primavera, and Gorman, 1987)	Asking for feedback Pacing procedure Pacing speech
On-the-job performance measures of person-centered care (Boettcher, Kemeny, DeShon, & Stevens, 2004)	Responding to need driven behaviors Use of unique details of resident's lives Respecting individuality Encouraging independence

Inductive inquiry, specifically qualitative description, requires that results are data-derived; when data did not support these previously published conceptualizations, modifications based on this inductive approach were proposed (see Discussion).

Parent Study

This dissertation research was a secondary analysis of existing video-recorded data collected in a quasi-experimental study that examined the effects of analgesia and psychosocial approaches to prevent and reduce pain during morning care in nursing home residents with dementia (hereafter called the parent study). Video-recorded data are particularly amenable to the study of detailed human interaction such as is involved in caregiving (Warnock & Allen, 2003). Video-recorded data are superior to real time observational data in that the investigator has the opportunity for microanalysis through repeated viewings (Spiers, 2004). Video recording is increasingly used in clinical research with persons with dementia precisely because it allows for multiple detailed observations, capturing behaviors that would otherwise be inaccessible in more traditional real-time observational methods. Because some persons with dementia use behaviors as a primary form of communication, slowly paced, repetitive observations of behaviors and facial expressions are important for optimizing research endeavors that seek to understand their needs (Morse & Bottorff, 1990, Warnock & Allen, 2003). This form of data maximizes research activity with persons with dementia who, because of their cognitive impairment and resulting communication deficits, are often unable to fully participate in more conventional forms of qualitative data collection.

For the parent study, 144 episodes of morning care were video-recorded, comprised of 15 certified nursing assistant [CNA] caregivers and 16 persons with dementia recruited from 3 nursing homes in a major metropolitan area of the Pacific Northwest. A research assistant [RA] trained in videography recorded each morning care episode and sought to be as unobtrusive as possible. Filming was done with a hand-held digital video-recorder. Whenever possible, the RA positioned herself so that the camera captured the face of the person with dementia.

The video-recorded data consist of morning caregiving episodes that include activities associated with getting ready for one’s day, including getting out of bed, getting dressed, grooming, oral hygiene, and toileting or changing incontinence products. In the parent study, morning care was defined as beginning when the CNA caregiver first approached the person with dementia in the morning to get them up and was considered to have begun when the CNA caregiver prompted the person with dementia with a statement such as, “Good morning, I’m here to help you”. Morning care ended when the CNA caregiver stated, “We’re all done now”. An episode of morning care was considered complete if at least one activity took place and either 45 minutes passed or the person with dementia was left alone for more than 10 minutes.

Original Study Participants

Certified Nursing Assistant Participants. Fifteen CNA caregivers participated in the study. Descriptive data was provided on 13 of the 15, with two caregivers declining to share this information. The participants were 87% female, ranged in age from 22 to 61 and had between 6 months and twenty years experience as a CNA. There was considerable diversity in this group: Asian/Pacific Islander (6.7%), Black (26.7%), Hispanic (26.7%), and Caucasian (26.7%). Four CNA caregivers spoke a language other than English as their first language. During the original consent process, each CNA caregiver consented to the video-recorded data being used in future research.

Participants with Dementia. The 16 participants with dementia were 65% female, 100% were Caucasian, and each had a diagnosis of either Alzheimer's disease or other dementia (Miller et al., 2005, Talerico et al., 2006). The participants ranged in age from 60 to 93 with a mean age of 83.2 and a median age of 84.

Based on Albert and Cohen's (1992) Test for Severe Impairment (TSI), a quantitative measure with possible scores ranging from 0 (very severely impaired) to 24 (moderately impaired), all participants had severe dementia. The TSI has been validated for use in populations scoring less than 10 on Folstein, Folstein and McHugh's (1975) Mini Mental State Exam. The mean score on the TSI for the16 participants with dementia in the parent study was 7.5.

Functional status was measured using the scale of ADLs developed by Morris, Fries and Morris (1999) that looks at 7 activities of daily living including bed mobility, transfer ability, locomotion on unit, dressing, eating, toilet use, and personal hygiene. The scale has a range from 0-28, with 28 indicating higher function. The 16 participants with dementia in the parent study had a mean score of 14.1, with a standard deviation of 8.4. This is suggestive that on average, a moderate level of assistance was required. Most were non-verbal or had very limited verbal communication capacity.

The original consent process involved consent from surrogates, most often a spouse or adult child. At the time of the original consent, each surrogate consented to the video-recorded data being used in future research.

Procedures

Selection of episodes

An initial viewing of all episodes of care in the data set (n=144) was done to determine: a) the quality of video, (e.g., the lighting was such that it would be possible to view both the caregiver and the older adult, the audio quality was sufficient to hear both members of the care dyad); and b) a cursory rating of caregiving quality for purposive sampling. Caregiving quality was rated on a scale of poor, fair, good, very good, and excellent. Rating within these categories was not well defined, in large part because this was seen as substantial overlap with the overall aim of the study. In order to determine this cursory rating, the investigator drew from an amalgam of years of clinical experience in nursing homes, clinically-based education, and knowledge derived from the scholarly literature. Additionally, assumptions guiding the study informed this initial rating; for an overview of these, see Appendix A. Table 2 provides brief definitions for each rating category.

Table 2. Rating scale for purposeful sampling based on caregiving quality

Rating Category	Definition
Poor	Rough handling, terse tone in verbal communication, rushed pace, majority of tasks are done in silence
Fair	Task-oriented, minimal-level, basic care, hurried pace, limited information offered about tasks
Good	Largely task-oriented, caregiver is in control, but is polite and friendly in approach, information is provided for the older adult, some attention to comfort
Very good	Caregiver expresses interest in the resident’s well-being, is attentive to comfort and warmth, provides kind and gentle care
Excellent	Older adult seems to be in the lead, caregiver is seen deferring to the resident when possible

Reflexive memos were kept through this rating process. An example entry follows:

> 516-1: basic good care – appears to be keeping patient as warm as possible. The person with dementia says, "oh boy, oh, boy, and oh God". Caregiver assumes this is negative and says, "we're almost done". What if he was expressing something positive? Occurred during towel bath. What if the massage she was providing during the bath felt good?
> I notice that my initial impression of the caregiver may be very good or even excellent, but then I'll go back and change it to 'good' or 'very good'. Why? It seems I do this because the care is kind, but then I realize it's very task oriented. There's no individual interaction going on really. Just telling the person what's happening. Other than periodically saying the person's name in order to get their attention, the care could be given to any patient with similar characteristics. Seems more likely to happen with patients who are passive in the receipt of care. But, it's still good care.

Methodological memos were also kept for each episode, documenting video quality, characteristics of the quality of care, and characteristics of the older adult. Sample entries follow:

> 546-2
> **Video quality:** no problems
> **Caregiving impression:** Fair, with some periodic good interactions. Early on, caregivers are giggling and can't seem to stop. Basic care strategies for people with dementia are not always followed, such as letting the person know what will be happening next. Task oriented.
> **Patient characteristics:** Verbal, but no words, ambulatory with minimal assistance. Resistive with care, requires two caregivers.
> 546-3
> **Video quality:** no problems
> **Caregiving impression:** Excellent – patient appears to be in control. A dance of caregiver's agenda and patient's desire. Beautifully gentle strategies to assist patient toward waking… Very patient.
> **Patient characteristics:** Verbal, ambulatory, hard of hearing, passive with care.

Of the 144 episodes of care, 17 were identified as *excellent* and another 17 were identified as *very good*. From these 34 purposefully selected videos, further selection was done based on variation within the care dyad to reflect a range of communication and functional abilities of the older adult and interpersonal style of the caregiver. Table 3 provides a brief description of the dyads observed, described, and analyzed for this study.

Table 3. Description of care dyads making up study sample

Caregiver Description	Care Receiver Description
Male 1	Female, intact verbal skills, ambulatory, precise and exacting personality, perseverating behaviors, ADL support and direction required, generally cooperative
Male 1	Female, verbal, but with moderate expressive aphasia, ‘chatty’, ADL assistance required, hallucinations, ambulatory, generally cooperative
Female 1	Female, parkinson’s symptoms, essentially non-verbal, significant rigidity, unable to assist with ADLs, non-ambulatory, passive with care
Female 1	Female, vocal, minimally verbal, extreme resistiveness at times, ambulatory, passive with care task completion (either fought care or passively allowed care)
Female 2	Male, verbal, but only very brief comments/responses, very passive with care, primarily used wheel-chair, one person transfer, hands-on ADL assistance required
Female 3	Male, verbal, able to express needs and respond to questions, used walker for ambulation, hands-on ADL assistance required, passively cooperative with some vocal resistance

Evolution of coding scheme

A coding scheme was developed using the procedures described in the following section. In general, discreet interaction descriptors (codes) were categorized, refined, and then rated as positive, negative, or neutral interactions. The positively rated categories and codes and their associated descriptors resulting from observation of the data were then analyzed as to whether they were person-centered or not.

The first step in the overall process of developing the resulting coding scheme was the transcription of the verbal contents of the entire episode. Next, a narrative description of the overall episode was written to provide a broad picture of the events in the episode. To guide this level of description, the questions below were addressed for each episode, focusing on the actions and interaction aspects of the caregiver.

What's going on here? (gestalt)
What are the characteristics of this case/What makes this case 'excellent'?
What is not excellent about what is going on?
What is not excellent about what's not going on?
What is unique about caring for this resident as opposed to other residents?

A sample of raw narrative description follows:

What's going on here? (gestalt)
Excellent dementia care. Quiet manner, gentle tone and a sense of graciousness, patience, and calm. While the vast majority of the conversation is task oriented, it seems that this resident might be overly distracted by tangential conversation. There is a lightness to their interaction, some laughter, not taking themselves too seriously. He attempts to give her as much control over events as possible, helping when the cues are there that it's time. He gives plenty of attention to her needs and particular ways. There's a back and forth pace here, a move toward task completion, then a waiting for her, allowing her to address the details before moving on. There is no hurriedness, no stress or pressure in the timing.
What are the characteristics of this case/What makes this case 'excellent'? He is astutely attentive. He is sincere and calm throughout. His tone of voice is positive, often encouraging. He gently explains things to her, making suggestions in order to gain her cooperation. He addresses her concerns, seeks to meet her expressed wishes, without any sense of irritation or frustration that this is delaying task completion. He makes positive eye contact, often bending to her eye level. He often uses hand gestures to support his verbal requests. He looks at her directly, seemingly to observe for changes in expression or any other cue that would offer guidance about how the care process is going. He is attentive to details of comfort and preference.
What is not excellent about what's going on? At times, he neglects to give any kind of warning, requiring that she ask what's going on. Not sure that's necessarily bad, since this resident is able to observe and ask about care, but he's not always proactive. If she's rather anxious, more information and preparation for events may be better than less information.
What is not excellent about what's not going on? He does not introduce himself or the care process in any way. He never uses her name.
What is unique about caring for this resident as opposed to other residents? She (resident) tends toward being anxious, anticipating the next steps. She demonstrates some perseverative behaviors. She is quite capable overall, both verbally and in ADL ability. She expresses her particular wishes, and is fastidious about certain things. She requires a tremendous amount of patience and skilled distraction and motivation. In some ways, he is just a facilitator of morning care. She needs gentle guidance and a bit of structure and assistance with task completion.

Following this gestalt-level description, analytically-meaningful clips were made of the episode being coded. This process involved inserting time-stamps into the transcript, which then served as a platform for clip creation. The beginning and end point of each clip was intended to be a discreet exchange of either activity, dialogue, or both. The nature of the data was such that this was not always a clean process, but clips created virtual lines in the observational data for line-by-line description. When there was no verbal exchange during a clip, this was indicated in the transcript with the word “action” for the corresponding member of the dyad. Typical clips were between 8 and 12 seconds in length. From each individual episode of care, 23 to 46 clips were created, depending on the original episode length and intensity of interaction bits. All episodes ranged from 3.5-29 minutes, averaging 11 minutes. Episodes selected for this study averaged 12 minutes (4.49 – 15.12) Clips varied in length since they were selected based on interaction exchanges, so if the interaction level was intense, the clip would be much shorter than when an exchange or activity was sparse, but average was 21 seconds. There was an average of 35 clips per episode.

Initial descriptive coding. Initial description/coding involved a line-by-line examination of the events in each individual clip, coding both the contents of the transcript associated with the clip and the actions observed in the associated video segment. Broad anchoring categories, (e.g. Caregiver Verbal Content, Caregiver Nonverbal Content, and Task Description) were developed early in the description process and provided a framework to focus the investigator’s attention to important observable aspects during coding. This essentially resulted in a three-layer approach to coding: description of the caregiving task, description of the caregiver’s verbal content, and description of the nonverbal aspects of caregiving (e.g. tone of voice and pace of care). The actual categories are found in Table 4 below. A miscellaneous category was used when these seemed ill-fitting. Prior to developing this framework, attention to detail during coding drifted considerably, even after a short period of observation. Because of this, it was necessary to re-view and code two episodes a second time to improve comprehensiveness of the description. After this framework was in place, it was used to ensure that each of the categories and subcategories within the individual clip had been addressed.

Table 4. Initial categories and subcategories developed for coding

Dyad Member	**Category**	**Subcategory**
Both	Description of task	No Subcategories
Caregiver	Verbal Content	Initiated by caregiver In response to older adult (including actions)
Caregiver	Nonverbal Content	Eye Gaze Volume of speech Tone of voice Facial expression Touch Spatial relationship Gestures Pacing
Older Adult	Verbal Content	No Subcategories
Older Adult	Vocalization quality	No Subcategories
Older Adult	Nonverbal content	Eye Gaze Facial expression Participation level in task Posture

The initial descriptive coding process required repeated examination of each interaction exchange, and a cognitive process that entailed answering, very concretely, the following question of each clip, “At the most basic level, what is the caregiver/older adult actually doing and/or saying?” Discreet descriptive codes then began to develop within the above framework in response to this question. When a new code was observed, it was given a label and a corresponding definition, capturing a detailed description of the code. Throughout this coding process, both methodological and reflexive memos were kept as observations of a more abstract nature arose, capturing the concordant analysis that was occurring alongside the description.

Informational redundancy. Early in this inductive process many codes were observed repeatedly, especially within the nonverbal categories, where the subcategory of ‘eye gaze’ for example, was defined by six discreet codes (direct eye contact, watching, glancing, looking at resident’s face, focused on the activity, or unable to observe). For these less complex categories, a code list reached saturation early in the observations. Informational redundancy also became evident early under the broad Caregiver Verbal Content category, even within a few clips of the first observed episode, in what later developed into the subcategories of Instructing and Explaining. After coding four complete episodes, informational redundancy, or categorical saturation, was evident across all broad subcategories (e.g., Explaining, Asking questions, Complimenting, Instructing, Responding to Actions).

At this point, the investigator moved to an approach that incorporated both inductive and deductive strategies. This step involved inductively viewing and coding additional videos with an eye for any new codes as well as deductively reviewing existing codes for their presence in the additional videos. The deductive process served to confirm previously observed codes and allowed more descriptors (codes) to develop within subcategories. No new subcategories emerged from this process, despite observing two different caregivers and two different older adults. After observing and coding these two additional episodes in this manner, a total of six complete episodes of morning care had been coded and the investigator and the dissertation committee were confident that informational redundancy had been reached at the subcategory level. Informational redundancy is important as it provides a foundation for the determination of the comprehensiveness and categorical precision of findings (Strauss & Corbin, 1998).

Data Analysis

Code Refinement

Refinement of codes followed the completion of coding the six episodes. This data reduction process involved examining all resulting codes thoroughly, comparing and contrasting each code with other codes to clarify those with overlapping definitions, or assessing for the most logical fit within subcategories that emerged. Consideration of the code, its associated definition and the category definitions was a critical part of this process, ensuring that codes themselves and corresponding definitions reflected the data as observed and with as much precision as possible. This often required repeated viewing of clips to which a particular code was attributed to allow for the comparing and contrasting of individual codes. Some label names were changed at this stage to improve clarity. This analytical process resulted in 24 subcategories (16 verbal content, 8 nonverbal), and 116 total codes (78 verbal content, 38 nonverbal) specific to the caregiver. Reflexive and theoretical memos were kept to capture the thought process of the investigator throughout the course of code refinement.

Code refinement was limited to the broad categories that were specific to the caregiver (Caregiver Verbal Interaction Content and Caregiver Nonverbal Interaction

Content), staying focused on the study aim. As stated previously, the intent of coding related to the caregiver was to describe, at a concrete level, what the caregiver's actions and words were toward the person receiving care. At a most basic level, these concrete codes were either a) descriptors of what the caregiver did or said independent of the older adult, or b) descriptors of what the caregiver did or said in direct response to something the older adult did or said. For example, if the older adult was resting quietly when the caregiver approached for care, the caregiver informing the older adult that care was about to begin would fall under the first dimension while a caregiver providing information about a task because the older adult asked a question fell under the latter dimension. Appendices B and F provide the raw descriptive codes from these two broad categories and dimensions after the refinement process.

Data Reconstruction

Caregiver Verbal Interaction Code Reconstruction. Next, the 78 refined verbal content codes were rated as positive, negative, neutral, or person-centered. See table 5 for categories within the continuum. Inherent within this rating mechanism was the understanding that a positive rating required some relational engagement; that is, affirming actions and/or words that were focused on the older adult in a way that fostered general well-being. The underlying assumptions guiding these determinations were the same as that used for the initial rating of each episode of care. See Appendix A for an overview of these assumptions.

Table 5. Rating scale for refined verbal content codes

Rating category	**Description**	**Example code**	**Example code description**
Positive and associated with good	Clinical experience and literature	Informing about next task	Usually uni-directional, CG tells resident some

care	suggest this is an aspect of good caregiving or dementia care		information about the 'what' of present or future activities. Or, CG may tell the resident that he's leaving the room for some purpose.
Positive and potentially person-centered	Initial impression is that the code and corresponding definition fits conceptually with the guiding definition of person-centered care	Asking for feedback about caregiving	CG specifically asks resident for input about the process of care delivery.
Uncertain	Needs further observation and/or analysis for rating	Using plural pronouns	CG says 'let's', 'we', or 'our' when instructing or giving information to the resident. For example, “We’re going to swing our legs to the edge of the bed.”
Neutral	Holds neither a positive or negative connotation	Repeating the resident's response	In response to a resident's verbalization, CG repeats what the resident says.
Negative	Clinical experience and literature suggest this would detract from good dementia care	Commenting about a negative habit of the older adult	CG says something about a negative habit of the resident. Uni-directional; CG doesn't appear to be expecting a response.

There were 52 codes classified as positive (33 associated with good care and 18 potentially person-centered), 9 uncertain codes, 13 neutral codes, and 5 negative codes. See Appendix C for results of this classification process.

Determining 'Person-centeredness'. The next analytical step involved a determination of which codes and definitions represented person-centered caregiving interactions. Determination was made based on the investigator's understanding of the theorized critical attributes of the construct of person-centered care as discussed in the literature. Analysis focused largely on whether or not the code/definition reflected an integration of these critical attributes. In other words, the attributes were not considered independent of one another. Caregiving interactions that displayed one, but not all attributes were not viewed as person-centered. To accomplish this step, each of the 18 codes classified as potentially person-centered and the 8 uncertain codes with each of their corresponding descriptions were examined in depth as to whether each was uniquely and independently person-centered or not. Theoretical memos were kept throughout this analytical step and rationale for the resulting determination was documented. Those 34 codes initially classified as positive but associated with good care were not analyzed further because on initial consideration, it was clear that at least one critical attribute of person-centeredness was not represented, eliminating it from further evaluation.

During the process, the investigator recognized that some codes and corresponding descriptions appeared to approximate person-centered care, but as observed in the data, there was some limiting aspect to the activity or words being fully representative of all person-centered attributes. For example, the code <u>asking about likes and dislikes</u>, which carries the data-based description: "Asking resident, in a yes/no manner, about their like or dislike of an object," at face value, appears positive, and is oriented toward the person receiving care. But, as it was actually observed in the data, the interactions appeared to be missing something critical. In one clip with this code, the caregiver asked this question with a bland tone, not making eye contact, and speaking and moving quickly. There was no time for the resident to respond to the question, making it appear to be a perfunctory gesture rather than a question to gather information about the person's likes and dislikes.

This gave rise to an important analytical observation. Some raw codes, as labeled and described, were not clearly person-centered without a corresponding person-centered interpersonal or non-verbal context. The fact that caregiver interactions in the data set did not always contain this critical interpersonal context was a limitation of the data set. In response to this limitation, the investigator identified codes with this issue as *toward* person-centered care, meaning that a critical element of person-centeredness was missing. This was in contrast to those codes that, as labeled and described directly from the data set were arguably person-centered, such as <u>asking clarifying questions</u>.

With the committee's input a decision was made to address this concern with an additional analytical step. This included a theoretical exploration with an aim to close the gap between those codes in the observed data identified as *toward* person-centered care and the more abstract construct of person-centered care. Essentially, the process involved consideration of the following question of each code, "If this interaction code was to be truly person-centered, what would it look like?" Using the data driven codes as a foundation for this more theory-building step, each code was analyzed, and a theoretical picture of what would make the interaction person-centered was documented. As in the previous analysis, the theoretical underpinnings of the study provided the basis for this exploration. This required either a revision to the original code or revision to the description of the interaction characteristics.

Additionally, as codes were reduced and organization of codes progressed, an iterative process of analysis continued. In particular, the categories of Negotiating Resistance and Adjusting Care seemed thin, in that only two codes reflected strategies of these label. The investigator returned to observation, focusing on those clips identified with the raw codes *negotiation, suggesting an alternative,* or *offering a different perspective* with an aim to observe for the process of negotiation or the process of adjusting care. The investigator also returned to clips that had surfaced as demonstrating exemplary interaction skills. After reviewing these 14 clips, three additional codes (*following the lead of the person receiving care, repeating an action to improve resident's response, beginning activities again)* were evident and included in further analysis.

Documentation of the conclusions of these processes is found in Appendix D. The result of the person-centered determination process resulted in a total of 17 discreet codes determined to evidence integrated characteristics of person-centeredness.

Comparison with labels from extant literature. Next, these 17 person-centered codes were compared to the a priori labels identified in the literature (Table 1). Each of the literature-based provisional labels and its corresponding definition was simultaneously analyzed along two lines. The investigator reflected about whether the provisional label agreed with both the broad defining attributes of person-centered care guiding the study and the 17 person-centered codes in order to determine whether the a priori label offered additional categories or preferred language for code names.

This process served two purposes. First, thoroughly examining the deductively derived labels for agreement with the observed codes and descriptions provided more robust findings by requiring additional consideration and analysis of the existing literature. Second, the process itself served as a validation of the inductively derived codes, confirming that the findings did indeed follow the theoretical understanding of the construct. Determinations and an associated rationale about inclusion or exclusion of each extant literature label are found in Appendix E. Through this process, the investigator gained clarity around the categorization of the inductively derived codes and strengthened the rationale for inclusion of the codes into the developing glossary.

Caregiver Non-verbal Interaction Code Reconstruction

Nonverbal interaction code reconstruction was similar to the process undertaken with the verbal interaction code analysis. Eight subcategories developed within the coding process. These were then refined, examining each for conceptual redundancy or excessive ambiguity. This process entailed viewing and re-viewing segments with relevant nonverbal codes at the clip and episode level. Additionally, reflexive memos, theoretical memos and gestalt-level descriptions of episodes were examined, adding depth to the analytical process. After code reduction, there were 37 codes within this broad category (Appendix F).

Determination of the Nonverbal Interaction codes as necessary for person-centered caregiving interactions developed through an iterative process of analysis. First, codes that carried a negative connotation (e.g., hurried pace, perfunctory tone, or coercive touch) were eliminated from consideration. This left 28 codes that were determined to be positive (e.g., eye gaze/direct, tone of voice/sincere) or neutral (e.g., eye gaze/focused on activity, tone of voice/matter of fact). At this point, nonverbal interactions were viewed in context with clips of verbal interactions that were determined to be person-centered to aid in describing the nonverbal aspects to person-centered interactions. Nonverbal interaction codes were also examined during comparison with the extant literature labels, helping to gain conceptual clarity. Subcategories were then considered separately, asking the question of each, "What does person-centered eye gaze (body orientation, facial expression, etc.) look like?" Answering this question required deliberation of the data, extant theory, literature-based recommendations, and the investigator's clinical knowledge and experience. While the aspects of nonverbal interaction were not determined to be independently person-centered caregiving interactions, they are deemed essential to the delivery of person-centered care and reflect the provisional label *Respecting Individuality*. Eight principles of nonverbal interaction were developed that are determined to be necessary to support the identified person-centered verbal interaction categories and codes. While it would have been useful for consistency and congruence in the results, the development of principles was more fitting to this aspect of the data in which description was more subjective and person-centered determination less precise. The nonverbal aspects were not well-suited to a glossary-style of presentation.

Development of Conceptual Diagram

As the data reconstruction phase neared completion, a conceptual diagram was developed to display study results. The development process included repeated viewings of isolated clips as well as merged clips of interactions that were coded with the particular code of interest. Essentially, a theoretical amalgam of exemplary person-centered interactions developed and, together with the theoretical extensions of the data, the conceptual diagram representing person-centered interactions during care resulted. No one clip is a full representation of the diagram. Four exclusively data driven verbal interaction subcategories (Seeking Guidance, Clarifying Ambiguity, Negotiating Resistance, Adjusting Care) organized the 12 person-centered codes while two of the verbal interaction subcategories (Validating Satisfaction and Recognizing Resistance) developed from more theoretical analysis. The data-derived categories are a result of the data reconstruction process that was provided in the previous section. An overview of the development process of the two theoretically derived categories follows.

Validating Satisfaction. Verbal interactions related to validating the resident's satisfaction with care were not overtly observed in the data set. As the other categories developed, a conceptual gap appeared that was not addressed by the observations. In essence this was the question of how a caregiver knows things are going well. Congruent with person-centered ideals, person-centered interactions necessitated incorporating some means of determining whether the resident's needs and preferences were being met so that caregivers were not independently relying on their interpretations or assumptions within the caregiving exchange. Discussing this gap with the committee led to the identification of the theoretical concept of validating satisfaction. In this qualitative study, it is important to recognize the deductive origins of the concept. It is included in the conceptual diagram to provide a more complete conceptualization of person-centered care interactions during hands-on care, based on the broader theoretical construct, but was not data-derived.

Recognizing Resistance. Another theoretically developed concept is that of recognizing resistance. The non-observable, but necessary cognitive process of a caregiver becoming aware of a resistive state in the person receiving care was critical to a more comprehensive conceptual diagram. This was true in that it is this process that provides the cognitive prompt for the caregiver to initiate the strategies associated with the data-derived category of Negotiating Resistance. This indirectly observed category was identified as a result of discussion with the dissertation committee and analysis of clips coded with any form of non-cooperation from the resident, thinking about the precursors to negotiation.

Expert consultant feedback

Following this stage of analysis and the development of the conceptual diagram, categories and corresponding codes were presented to five consultant groups or individuals as described below in the methodological rigor section. Their feedback was incorporated into the final results, though few changes were necessary. Results of this comprehensive analytical process are provided in the following chapter.

Methodological rigor

Criteria recommended by Lincoln and Guba (1985) were used to assess the adequacy of the research process and substantiate the findings as reflective of the data. These criteria, often considered the gold standard for trustworthiness of qualitative research, are suitable for inductively driven studies that provide low-inference results, such as qualitative descriptive methods. Lincoln and Guba's primary criteria include credibility, dependability, confirmability, and transferability.

Credibility, whether findings are believable, were attended to in several ways. First, Lincoln and Guba's (1985) strategy of 'persistent observation' was the primary means for providing a foundation of the integrity of the findings. Investing sufficient time viewing and reviewing the data improves credibility in that the investigator is familiar with the data at a deep level, and is grounded solidly in the data, promoting greater understanding and more precise descriptions. Secondly, as a nurse-clinician in the nursing home setting and nurse-interventionist on the parent study, the investigator has extensive experience in the setting and with caregiving for persons with dementia. These participant-observer experiences provided an opportunity for ‘prolonged engagement’, a second strategy employed to enhance the credibility of findings. Through these experiences, the investigator gained firsthand knowledge of caregiving for persons with dementia that serves as a means of sensitizing the investigator to the events and interactions in the data (Strauss & Corbin, 1998).

A third strategy, ‘peer debriefing’, was used throughout the study, most often by dissertation committee members and qualitative dissertation seminar faculty and members, but also through the use of additional consultants. This strategy opened the findings up for critique to help ensure that identified categories and resulting conceptual definitions accurately represent the data.

Use of consultants. Critique and feedback from the dissertation committee and qualitative dissertation seminar faculty and student members that was provided throughout the study was primarily documented in methodological memos. Based on these ongoing discussions of the research process and findings, adjustments in procedures were made at the time the feedback was provided and are reflected in the overview of the study procedures noted in the previous section.

Formal critique was sought in separate one-time meetings with two clinical experts, Joanne Rader RN, MN, FAAN, Lynn Szender, RN, and also a group of CNA caregivers. Joanne Rader is a nationally recognized clinical expert in the topic area with over 30 years of long-term care experience, primarily in the theoretical and clinical application of person-centered care. Her service as a founding member and Pioneer Network Board Member, as well as her numerous articles, books, manuals and videos on dementia care have contributed to the high regard afforded her in the dementia care community. After reviewing an overview of the analytic process and results, including the conceptual diagram, on the topic area, Joanne Rader offered feedback via a face to face meeting. In general, her comments were positive, responding that the results were clinically relevant and would be beneficial to caregivers. She believed the categories to have face-validity based on her experience with providing care and advocating for person-centered care in nursing homes. She offered one particular area of concern regarding transferability and practical use of the findings. Her concern was that if caregivers were taught to implement the strategies as concretely described in Appendix E, there would likely be instances where the exchange would reach an impasse related to repeatedly deferring to the resident for permission to progress with care-related tasks. She offered critique suggesting that caregivers face this dilemma frequently, though strategies to address the complexity of these issues were not reflected in the conceptual diagram. Additionally, because the clinical use of the study results would rely heavily on the resident being an active participant in the caregiving process, she questioned the applicability of the results to all persons with dementia, or just a subset of residents with remaining verbal capacity. No changes to the findings were made based on these critiques; instead responses are found in Chapter 5, both in the discussion section and in the study limitations section.

Additional feedback and critique was sought from Lynn Szender, RN, a nurse-administrator at a well-respected nursing home in Portland, Oregon, Mary's Woods. She is recognized in the local area as a clinical expert in the content area. Under her leadership as the director of health services, her facility has been recognized by Oregon state agencies as making significant progress in changing the culture of the facility from an institutionalized model to one that provides person-centered care. The process for feedback was identical to that of Joanne Rader's. Again, the overall comments were positive and results were believed to be of value in reaching the aim of the study. Discussion during this meeting similarly focused on the gray areas of decision making that caregivers confront during hands-on care, particularly related to 'asking permission'. The point was raised that when caregivers receive a decline to begin care activities in response to asking permission, some caregivers will default to ending any further pursuits to complete morning care tasks. Practical strategies to address these challenges are not directly addressed by the study findings. Again, no changes were made in direct response to this feedback. A more general response to this concern is addressed in the discussion chapter.

Dependability and confirmability were addressed via an inquiry audit. Dependability, a parallel concept to reliability in quantitative research, is the degree to which the analysis has produced an accurate portrayal of the phenomenon that is consistent with the data. Both dependability and confirmability, whether results can be authenticated, were enhanced with thorough documentation of the research process via methodological memos, providing an audit trail. With methodological memos, the investigator documented issues relevant to the research operations and procedures. As the coding process neared completion, the six qualitative dissertation seminar members served as objective auditor, uninvolved in the research, and conducted a formal inquiry audit to evaluate both the process and the findings of the study, using the guidelines provided by Halpern (as cited in Lincoln & Guba, 1985).

A formal inquiry audit was conducted after the completion of coding, serving as a methodological audit of the data reduction process. The auditing team was made up of members of the qualitative dissertation seminar, including one faculty member with expertise in qualitative methods and five doctoral students. Direct feedback from members of the audit team suggested “methods and beginning analyses were verifiable and systematic” which indicated that the study was credible and trustworthy at this point (data reduction). Having video clips available for the group was very helpful in coming to this conclusion.” (personal communication, Juliana Cartwright, 2009).

Two concerns of import were raised during the audit. The first was related to the sampling plan. The lack of a detailed behavioral description of the criteria for the initial selection of clips to view at the outset of the study was noted. This was rectified by developing a rating scale detailing the investigator’s perceptions during the initial cursory viewing and selection process (Table 2). Second was a concern regarding availability of theoretical memos that guided the process of organizing and labeling the data. The auditors advised that the theoretical context should complement the methodologic decisions and also tie to the raw data for the remainder of the study. This concern was addressed by the investigator memoing somewhat differently subsequent to the audit. Previous to the audit, memos were written in a combined fashion, making the identification of specific theoretical memo content within the memos difficult. After the audit, a concerted effort was made to separate out this content when memoing, creating an audit trail that was easier to follow.

Transferability is the degree to which the results are described so as to allow the reader to determine whether the resulting conceptual definitions are applicable to other settings. Ultimately, the usefulness of the study's results is ultimately determined by the consensus of those who would use them. With this perspective in mind, thick, contextual based descriptions have been provided to enhance this determination by the user. Findings are considered dynamic, remaining open to refinement as they are applied and tested in various settings.

Transferability was vetted in two similar arenas. First, the investigator conducted a meeting with a large group of nursing home CNAs who cared for people with dementia. The purpose of the meeting was for general discussion of the findings of the study. The comments and experiences of this group were in agreement with the findings of the study and the investigator's experience of issues in dementia care.

After this large group meeting, a second meeting was held with three CNA caregivers who were identified by their nurse supervisor as exemplary in their care of patients with dementia. The aim of this meeting was to receive an assessment of the results of the study for clinical representativeness and adequacy. During this meeting, CNA caregiver consultants were provided an overview of the study and then participated in a presentation of the study results by the investigator. An open forum followed in which members discussed the relevance and comprehensiveness of the results. This meeting provided for more focused feedback specific to the conceptual diagram and code definitions. These caregivers were equally affirming of the study results. As an example, one male caregiver stated of the diagram, “This looks like just what we do”, suggesting that the diagram is sufficiently descriptive of person-centered, exemplary caregiving.

There were no concerns regarding the findings or their applicability to the population of interest. Lastly, the findings were opened to critique during a presentation at the annual meeting of the Gerontological Society of America. No criticism of methods or the findings was voiced at that time.

Reflexive Journal. To further augment each of these four methodological criteria, a reflexive journal was also maintained, in which the investigator reflected on those aspects of the analytic process that involved the investigator as a human instrument, noting the development of insights.

The use of a naturalistic design with qualitative description methods to analyze videotaped episodes of morning care provided by CNA caregivers to persons with dementia allowed for inductive concept development. The design incorporated a variety of standard processes to maintain methodological rigor. These included prolonged engagement, persistent observation, reflexive journaling, an inquiry audit, and multiple opportunities for feedback and critique. Through close adherence to qualitative descriptive methods, including purposeful sampling, observational, detailed description and coding, and content analysis, the investigator was able to identify person-centered caregiving interactions during hands-on care. These findings are reviewed in the following chapter.

CHAPTER IV

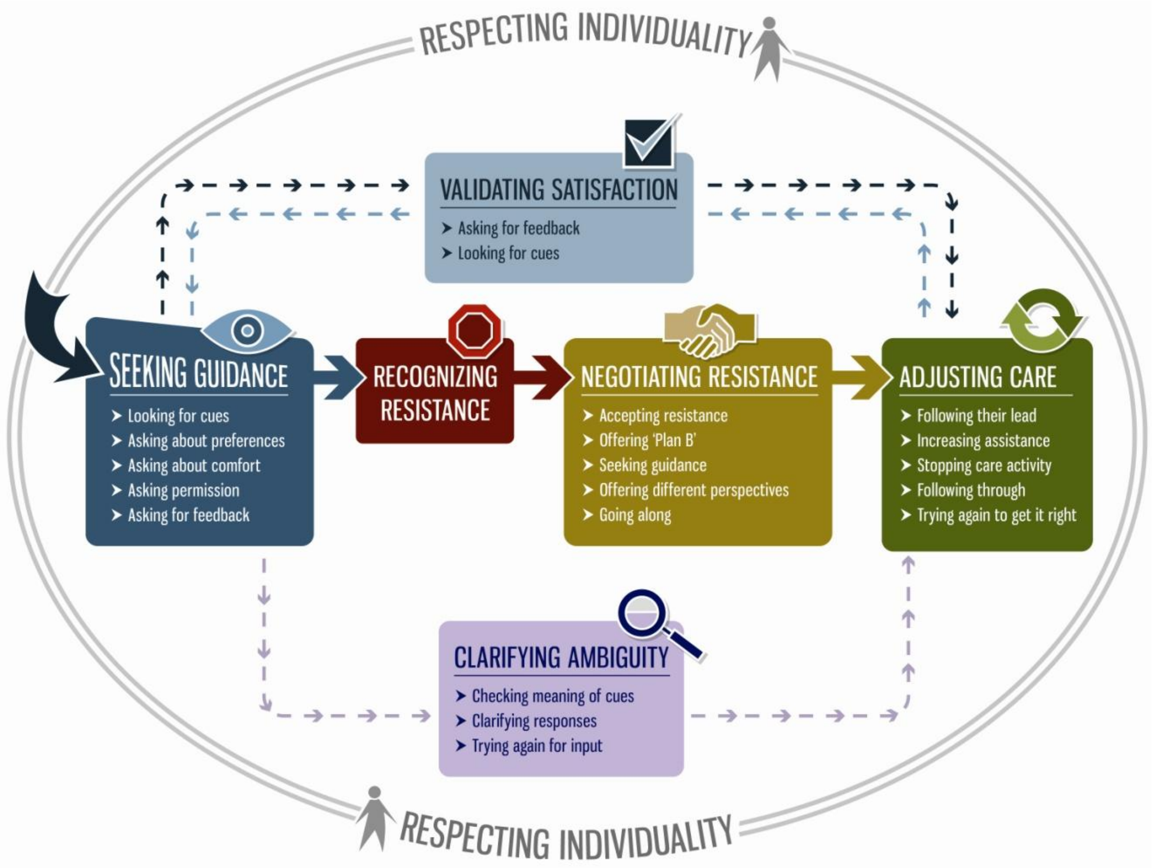
Results

Observable interactions within the six video-taped episodes of morning care analyzed in this study provided rich detail for in-depth descriptions. Within these descriptions, person-centered caregiver interactions were identified and organized. This results section is structured based on the conceptual diagram that resulted from the study. Briefly, analysis of caregiver interactions that were determined to be integral to person-centered caregiving for persons with dementia resulted in seven subcategories (*Seeking Guidance, Validating Satisfaction, Clarifying Ambiguity, Recognizing Resistance, Negotiating Resistance, Adjusting Care,* and *Respecting Individuality*), each with corresponding data-driven strategies or principles.

Conceptual Diagram

The provision of person-centered care is manifest through a complex interaction between the caregiver and the resident with dementia. The focus of this study was the caregiver. The actions, both verbal and nonverbal, of the caregiver which are essential to person-centered care are those that uniquely identify the individual needs and preferences of the person with dementia as care is being provided. These observed actions were determined to be person-centered through a comparison of each discreet action with the current literature-based understanding of this broad construct. A visual depiction of the complexity in interaction is provided in a conceptual diagram (Figure 1).

Figure 1. Person-Centered Caregiving Interactions in Dementia Care



A narrative overview of the diagram is provided, followed by detail of each individual subcategory and their corresponding codes. In general, person-centered caregivers begin the process of caregiving by seeking guidance. The information gathered through seeking guidance is ultimately used to adjust care so that these beginning and end points, seeking guidance and adjusting care, are critical to each discreet person-centered interaction. As caregivers sought guidance, various verbal and behavioral responses from the person with dementia required additional actions. If the response from the person with dementia was non-cooperative, caregivers were observed to begin negotiating resistance, dependent on the caregiver's recognition of the person with dementia's behavior as resistive. Adjusting care remains the primary goal of this process of negotiating through resistive behavior as the caregiver continues to seek the person with dementia's perspective and accommodate their preferences.

If the response from the person with dementia to seeking guidance strategies was unclear in any way, the person-centered caregiver would attempt to clarify ambiguity; here again the aim was to gather information in order to adjust care. If the response from the person with dementia was cooperative, person-centered caregivers assess this cooperation through validating satisfaction. These concrete actions are only person-centered when they are provided in a context of care that respects individuality. It was this respecting individuality subcategory that addressed the nonverbal aspects of human interaction.

The diagram depicts an iterative process of interaction that occurs throughout the caregiving episode. In this process, person-centered caregivers continually seek guidance in an effort to adjust care according to the immediate needs, preferences, and wishes of the person with dementia.

Person-Centered Verbal Interactions

Six subcategories were identified as verbal-based caregiver interactions associated with providing person-centered care. These were *Seeking Guidance, Validating Satisfaction, Clarifying Ambiguity, Recognizing Resistance, Negotiating Resistance, and Adjusting Care*. A total of 17 unique codes operationalize these subcategories and are the beginning foundation of a glossary of person-centered caregiver interactions. Appendix G provides a table of the glossary with subcategory definitions and corresponding code definitions. The following section details the subcategories with examples of the associated codes within each subcategory.

Seeking Guidance. The data derived subcategory of seeking guidance consists of active processes, both verbal and nonverbal, in which the caregiver solicits information for the current caregiving episode, putting the person receiving care in a position to direct the current care process as much as they are able. It is an active process of seeking to know the immediate needs, preferences and wishes of the person.

The five unique codes that are included in this subcategory include 1) looking for cues, 2) asking about preferences, 3) asking about comfort, 4) asking for permission, and 5) asking for feedback (Table 1). Most relevant to person-centeredness in these descriptors is the active process of avoiding assumptions and acknowledging the potential for variability in the care receiver's mood, fatigue level, and health status. This process is evidenced through the solicitation of information from the person with dementia. Each of the five codes associated with seeking guidance provides a means for the caregiver to collect relevant information for the current hands-on caregiving task and is thus central to a person-centered approach to caregiving.

Table 1. Seeking guidance subcategory and associated codes with person-centered definitions

Seeking Guidance: This is understood as those active processes, both verbal and nonverbal, (as in the case of 'looking for cues'), in which the caregiver solicits information for the current caregiving episode, putting the person receiving care in a position to direct the care process as much as they are able.		
	Looking for cues	During the process of completing tasks or independent activities, the caregiver looks at the face of the person receiving care.
	Asking about preferences	Asking the person receiving care about their first choice in care activities (e.g., the sequence of activities, how a transfer is done) and the range of choices that occur during each care

		episode (e.g., clothing items, buttoning a sweater or leaving it unbuttoned).
	Asking about comfort and pain	Either as a course of interaction or in response to some indication by the person receiving care, the caregiver asks the person receiving care about their comfort level, as well as asking directly about pain, as specifically as possible.
	Asking permission	Before initiating any care activity that requires hands-on assistance from the caregiver, the caregiver asks the person receiving care if he/she is ready to begin the process.
	Asking for feedback	Asking the person receiving care about their perception of the delivery of care.

Examples of the descriptive codes associated with seeking guidance will assist the reader in understanding this subcategory. For example, looking for cues was observed in caregivers who glanced at the face of the person with dementia or who watched as the person with dementia ambulated or independently performed another activity. Some examples of asking about preferences were when caregivers asked the person with dementia whether they wanted to wear a hat or whether they wanted to wear lipstick. Asking about comfort was observed when one caregiver asked, “Did that hurt?” In another clip with this code, a caregiver asked, “Are you hurting?” The code asking permission was assigned to clips in which the caregiver simply said, “Ok?” after letting the person with dementia know what step was next in the process of a task. An example of clips coded with asking for feedback was when a caregiver asked, “How was that?” after transferring a person with dementia from the bed to a wheelchair.

Negotiating Resistance. This subcategory represents the caregiver’s response to any degree of reluctance, resistance, or expressed dissatisfaction to the caregiving process by the person receiving care. Five codes describe strategies within the subcategory of negotiating resistance. These are 1) accepting resistance, 2) offering a plan B, 3) offering a different perspective, and 4) going along (Table 2). Additionally, the actions associated with codes in the broader category of <u>seeking guidance</u> were also observed and are included as a whole in the subcategory of <u>negotiating resistance</u>.

Table 2. Negotiating resistance subcategory with associated codes and person-centered definitions.

<u>Negotiating Resistance:</u> The caregiver's person-centered response to any degree of reluctance, resistance, or expressed dissatisfaction to the caregiving process by the person receiving care.	
Accepting resistance	Verbally acknowledging and respecting the expressed reluctance or resistance of the person receiving care. In so doing, the caregiver creates an environment of non-resistance, choosing to meet resistance with acceptance rather than more resistance.
Offering a plan B	As part of the negotiating process, the caregiver suggests an alternative to the current course of care.
Offering different perspectives	Within a process of negotiation, the caregiver offers his/her perspective of the situation. The intent is to move the person receiving care past a point of perseveration so that care can move ahead.
Going along	At the end of the process of negotiating, the caregiver defers to the person receiving care, either asking for permission to move forward with the negotiated new plan or simply beginning to act on the plan indicated by the person receiving care.

Codes in this subcategory were not observed in a linear fashion, nor were all of them evident in every episode of negotiation. However, a hallmark of person-centered negotiation was that of 'accepting resistance', defined as verbally acknowledging and validating the resistance of the person receiving care. For example, the caregiver asks the resident if he is ready to get out of bed. He responds with a rather gruff "No." Instead of cajoling or urging, as seen in other clips, the caregiver simply offers an accepting "Ok" and stops any further movement toward the task. Within this interaction strategy, the caregiver creates an environment of non-resistance, choosing to meet resistance with acceptance rather than with more resistance.

Examples from the other codes operationalizing this subcategory follow. These strategies were observed as caregivers attempted to address resistance while allowing the care receiver as much control as possible. Offering a plan B was coded on one clip where, after accepting resistance as noted in the above example, the caregiver says, “Why don’t we try again in a few minutes?” She remains by his bed, makes eye contact, and gently massages his knee. There is no further resistance from the person with dementia. Another strategy, offering a different perspective, was observed at times when care receivers were dissatisfied with something about their appearance, leading to perseveration or anxiety. Attempting to negotiate around these instances, the caregiver responded by complimenting the person or reassuring them about their appearance. For example, in one clip, a resident is expressing concern in a somewhat perseverative manner that her outfit “Is just not right”. She has trouble moving past this concern. The caregiver offers a genuine compliment about the resident’s appearance which appears to reassure the resident, avoiding any escalation of the incident. Going along was coded in several clips. One example was in response to the caregiver’s offering a plan B to wash the resident’s face in bed instead of at the sink, the resident begins getting back in bed. The caregiver goes along, beginning to act on the new plan. Nothing more is said, but in the simple act of acting on the observed actions/response of the person with dementia the caregiver goes along. During incidents of reluctance or resistance, the person-centered caregiver skillfully employed these interaction techniques in order to progress in the morning routine.

Clarifying Ambiguity. During observation, many verbalizations from the person receiving care were difficult to understand, for at least two reasons. Some responses were simply not articulated clearly while others contained non-sensical words or phrases. Non-verbal cues were also present, primarily through body movements and facial expressions, but also through tonal qualities of vocalizations. The meaning of these types of responses and cues were unclear and difficult to interpret beyond attributing a general negative or positive quality to the cue. The act of clarifying the meaning of unclear verbal responses or vocalizations, as well as observed non-verbal cues and behaviors is crucial to person-centered interactions.

<u>Clarifying ambiguity</u> includes the caregiver's verbal interactions that assist the caregiver in optimizing all forms of communication from the person receiving care, especially those which leave the caregiver uncertain. Through these exchanges, the caregiver avoids misinterpretation and improves clarity about the communication by the person with dementia in order to adjust the care accordingly. There were three codes associated with this subcategory (Table 3). They were 1) checking the meaning of cues, 2) clarifying responses, and 3) trying again for input.

Table 3. Clarifying ambiguity subcategory and associated codes with person-centered definitions.

<u>Clarifying ambiguity</u>: includes verbal interaction from the caregiver that assists the caregiver in optimizing all forms of communication from the person receiving care, especially those which leave the caregiver uncertain. In doing so, the caregiver reduces the likelihood of making assumptions about the communication.	
Checking the meaning of cues	When the person receiving care displays a behavior, utters an unintelligible word or phrase, or vocalizes (e.g., moan), the caregiver asks directly about it, seeking to confirm or contradict his interpretation of the behavior, words, or vocalization.
Clarifying responses	When the person receiving care responds to a question generally or makes a comment that is general in nature, the caregiver asks

	additional questions in an effort to clearly understand the person receiving care.
Trying again for input	When the person receiving care has not responded to a question from the caregiver, the caregiver asks the question again, or asks for the information in a different way, making sure the person heard the question and was focused on the content.

Three codes operationalize this subcategory. These were 1) checking the meaning of cues, 2) clarifying responses, and 3) trying again for input. Each of these interactions requires that the caregiver make an attempt to clearly understand the needs and preferences of the care receiver. The caregiver seeks to verify interpretations of unclear verbal messages and nonverbal cues by asking the person about the attempted communication. Rather than ignoring unclear communications, a non-response, or relying on the caregiver's interpretation, the caregiver would ask again about what was said in order to understand the person.

Data-based examples of each of these codes follow. First, checking the meaning of cues was coded on a clip in which the person receiving care is waiting, without a blouse on, for the caregiver to help with upper body dressing. She begins a stuttering, unintelligible vocalization. The caregiver says, "Come on and hurry up, right?", asking the person receiving care if she is interpreting the vocalization correctly. In a clip coded with clarifying responses, the person receiving care is standing, commenting about her pants. She says, "It's a little bit too long now." The caregiver, clarifying her comment, asks, "Where, down here?" as he crouches down next to her feet. The person receiving care responds, "Hmm mmm." The code trying again for input was observed in a clip where the caregiver asks the person receiving care if he would like to wear his hat. He did not respond in any way. She makes eye contact, speaks in a volume he can hear, and says, “Gary, I’d like to know if you’d like to wear your hat today?” altering the question slightly and providing another opportunity for him to guide the care activity.

Validating Satisfaction. The subcategory of validating satisfaction is a theoretical operationalization of interactions defined as those activities which would assist the caregiver in knowing that they are meeting the care-receiver’s needs and preferences. The two strategies in this subcategory, looking for cues and asking for feedback are codes from the data-derived seeking guidance subcategory and are theorized as pointed ways of assessing or validating satisfaction. The essence of this subcategory is the avoidance of relying on assumptions that arise from caregiver interpretation during caregiving. Rather than assuming that cooperation or passivity is indicative of satisfaction, the person-centered caregiver actually asks about the care recipient’s perception of the care. For example, in a hypothetical scenario, a person-centered caregiver would simply ask, based on a smile (looking for cues) whether the caregiving task of the moment is going well (asking for feedback). A caregiver might ask, “Do I have it right now?” or “Am I doing things the way you like them done?” In doing so, the person-centered caregiver attempts to validate satisfaction.

Adjusting Care. Within the subcategory of adjusting care are the activities of the caregiver in response to new information from the person receiving care. Caregivers then attempted to incorporate the new information into the way he/she assisted the resident during the caregiving episode. In large part, this was the culmination of a person-centered interaction.

Five unique adjusting care responses were observed to provide a beginning operationalization of this subcategory. These were 1) following their lead, 2) increasing assistance, 3) stopping the care activity, 4) following through, and 5) trying again to get it right (Table 4). Each of these responses reflect some alteration of the way care was being done in the moments prior to receiving the information in order to better meet the needs and preferences of the person receiving care. It is these acts of adjusting care practices in response to the person's guidance that complete a process of person-centered interaction. Simply asking questions to understand the care receiver's preferences (seeking guidance) without acting on the information would undermine the fundamental assertions of person-centeredness, valuing the person and honoring the person's uniqueness.

Table 4. Adjusting care subcategory with associated codes and person-centered definitions.

Adjusting Care: An active response by the caregiver to new information from the person receiving care. This information may come by way of a corrective action, a comment or request, or some behavioral or vocal cue. The caregiver then attempts to incorporate the new information into the way he/she assists during the caregiving episode.		
	Following their lead	In response to an active cue from the person receiving care, the caregiver changes his/her immediate actions in order to verbally or physically assist the person receiving care.
	Increasing verbal or physical assistance	In response to an active or verbal cue from the person receiving care, the caregiver makes an adjustment to the way care was being delivered and increases the amount of hands-on assistance or offers more specific verbal cues so that the care receiver can complete the activity.
	Stopping care activity	In response to some behavioral or verbal/vocal cue from the person receiving care, the caregiver stops their activity. The time-frame for stopping care may vary. A simple pause may be sufficient in some cases; other circumstances may lead the caregiver to stop the activity in order to enter into negotiating care, or even to end the caregiving altogether in order to come back another time.
	Following through	In response to verbal expressions of need or preference, or action behaviors with a clear intent, the caregiver acknowledges the information and informs the person receiving care how he/she will address the information. 'Following through' also includes some action that indicates the caregiver is acting on the information received.
	Trying again to get	In response to a behavioral or verbal/vocal cue of

	it right	dissatisfaction or discomfort during a specific caregiving task, the caregiver performs the same task differently, repeating with slight adjustments to the action until the cues or feedback indicate satisfaction.

Data-based examples of clips coded with these individual strategies follow. First, following their lead was observed in a clip where the caregiver was nearby, preparing items for brushing teeth while the person receiving care is using the toilet. The person receiving care finished and began to stand before the caregiver was ready. The caregiver switches from the prep task to an assisting task, guided by the actions of the person receiving care. In increasing assistance, an interaction was observed with the person receiving care attempting to put on her shirt independently. The caregiver was nearby, drying off the sink. The person began to have trouble getting her head through the shirt and became stuck. The caregiver provided hands-on assistance for completing the upper body dressing, talking through the aspects of the task. An example of stopping the care activity occurred when a caregiver was attempting to lead the person receiving care to the sink to wash her face. The person pulled away from the caregiver and began vocalizations with a negative tone. The caregiver stops the attempt to lead and turns toward the person receiving care. In a clip coded with following through, the person with dementia indicated by action and attempted speech that she would like help with rolling up her sleeves. The caregiver said, “I can help you with that”, and began doing so, offering to do the second sleeve as well. Caregivers were observed trying again to get it right in one clip where the person receiving care voiced dissatisfaction with how her pants look and feel. The caregiver made a couple of very slight adjustments to the way the pants sit at her waist until she indicates it is the way she prefers. Each of these observed strategies operationalize the subcategory of adjusting care.

Person-Centered Nonverbal Interactions

Observations of the nonverbal interactions of the caregiver were organized into eight categories. The eight categories were pace of care, tone of voice, volume of speech, eye gaze, facial expression, purpose of gestures, spatial relationship, and purpose of touch,. Categories and associated codes, along with descriptors are provided in Appendix F. The observation and analysis of these nonverbal interactions resulted in eight principles determined to be necessary for person-centered verbal interaction. The eight associated principles follow:

1. When care is underway, the pace of care is calm, allowing for the resident to respond either verbally or physically. The caregiver waits, as needed, accommodating to the resident's speed of task completion or communication, recognizing latencies in cognitive processing.
2. Caregiving activity is paused or stopped when a) asking the resident about pain, b) apologizing for causing discomfort, or c) in response to any form of resistance from the person receiving care.
3. When the caregiver speaks, the tone of voice is positive and appropriate to the situation. The four resulting descriptors of positive tone follow:

   1) Interested: An engaging tone, conveys 'friendliness' toward the resident and interest in the resident's response. Content may include asking questions.

   2) Light-hearted: Pitch may be elevated slightly, quality is not serious or intense, but conveys simplicity and ease. Content may include humor or banter.

3) Sincere: Pitch may be slightly lower and without much variability. Conveys a more serious and genuine message.

4) Gentle: Soft and caring quality, volume may be quieter, pitch is steady. The tone conveys a sense of peace or soothing tenderness.

4. Volume of speech reflects the patient's needs, adjusting to hearing impairment as needed.
5. When not involved in a caregiving task that requires focused attention, the eye gaze is focused on the resident's face, attempting eye contact.
6. Facial expression is neutral or positive and friendly.
7. Body orientation is toward the resident whenever possible, attempting to get at eye level when appropriate, i.e. talking to the resident. Crouching is preferred rather than leaning from the waist.
8. Touch, when present, does not elicit a negative reaction from the resident.

These 8 principles are an amalgam of the observations of the nonverbal aspects, rather than discreet descriptions of codes. These are descriptive of Respecting Individuality, a label borrowed from Boettcher, Kemeny, DeShon, & Stevens, 2004. Respecting Individuality, as a subcategory, is defined as the nonverbal context of caregiving interaction demonstrating a value of the person's uniqueness and humanity.

From the description and analysis of six video-recorded episodes of morning care for persons with dementia, a conceptual model of person-centered caregiving interaction was developed. Subcategories and associated codes within the model provide a detailed glossary of person-centered caregiving strategies, attending to the primary aim of the study: to operationalize person-centered care at the level of hands-on caregiving. This inductively derived model incorporates both verbal and nonverbal aspects of caring, addressing the complexity of caregiving for the person with dementia in a way that reflects the attributes of the construct of person-centered care.

CHAPTER V

Discussion

The main findings of this dissertation research related to person-centered caregiving interactions were organized into two categories: 1) five foundational verbal interactions; and 2) eight principles of nonverbal interactions. The five verbal interaction categories with their corresponding, inductively derived implementation codes were Seeking Guidance (looking for cues, asking about preferences, asking about comfort, asking permission, asking for feedback), Validating Satisfaction (asking for feedback, looking for cues), Clarifying Ambiguity (checking meaning of cues, clarifying responses, trying again for input), Negotiating Resistance (accepting resistance, offering plan 'b', seeking guidance, offering different perspectives, going along), and Adjusting Care (following their lead, increasing assistance, stopping care activity, following through, trying again to get it right).

The interplay between interaction categories is an iterative process of person-centered care, with caregivers first Seeking Guidance, then identifying the response of the person with dementia, and then either Validating Satisfaction, Clarifying Ambiguity, or Negotiating Resistance, using the identified implementation strategies. Caregivers ultimately use these strategies and the responses from the person with dementia in order to Adjust Care (e.g., following their lead, stopping care activity, trying again to get it right), which is the conclusion of each discreet person-centered caregiving interaction. Identification of these five interaction categories is fundamental to the delivery and subsequent measurement of person-centered caregiving interactions, and thus is critical to nursing science dedicated to this topic.

The eight principles of person-centered care address 1) the pace of care, 2) priorities of caregiving activity, 3) quality of touch, 4) volume and rate of speech, 5) facial expression, 6) eye gaze, 7) tone of voice, and 8) body orientation. The resulting nonverbal behavioral principles provide the context necessary for person-centered caregiving interactions for people with dementia.

Discussion of the findings from this dissertation research must be considered with knowledge of the limitations of the study. The following section covers the known weaknesses. Subsequent sections address theoretical, clinical, and future research implications.

Study Limitations

This dissertation research has several limitations. At least two of these stem from the fact that data were limited to available videotapes from a previously conducted study. First, although the video-recorded episodes of morning care were rich with contextual details of caregiving interaction sufficient for the addressing the primary question of the study, it is important to note that the investigator found few episodes in which person-centered caregiving interactions were used in an extended manner over a large portion of the care episode. This paucity of person-centered caregiving interactions in the data suggests that while caregivers in the three study nursing homes had exposure to person-centered care ideals, they experienced difficulty in operationalizing those ideals. While this was expected to some degree by the investigator, and was essentially the impetus for the study's primary aim, the small number of interactions that were rich with caregiving interactions that were ultimately determined to be person-centered may have resulted in a less than comprehensive list of practical strategies (e.g., asking for feedback, trying again to get it right, following their lead) used by caregivers. A follow up study with caregivers in model facilities where person-centered care ideals have been long standing may address this limitation. This limitation does not however, appear to have reduced the comprehensiveness of the process of person centered caregiving interactions (e.g., seeking guidance, clarifying ambiguity, adjusting care) as evidenced by informational redundancy reached at this level within the six analyzed episodes of care.

Second, with the use of pre-existing data, the investigator did not have the opportunity to interview participants or collect additional data from these participants, neither the caregivers nor the persons with dementia. As a result, no information is known about the history of relationship within the care dyad, leaving open the question of the extent to which knowledge gained through previous caring episodes aid in providing person-centered care in the present. The study would have been strengthened, and more congruent with person centered ideals, if interviews were a possible part of the design. However, this limitation was addressed in two ways. First, the study design was restricted to inductive observational description of the data at a low-level of inference. Second, review of the resulting codes, categories and operational definitions by a clinical expert and practicing CNA caregivers contribute to the credibility of the results.

Finally, also because of the design of the study, aspects of the caregiver’s decision making processes are unknown. As a result, the issue of caregiver intention or the caregiver’s internal stance is not addressed. Of interest in this study were those discreet, observable, and potentially measurable caregiving interactions that exemplify person centered care ideals. It remains unclear whether a caregiver’s intention for person centered caregiving interactions is essential to the delivery of those interactions. Again, the results from this study, including these known limitations, will serve as a basis for exploring these and other important questions in future studies.

Theoretical Implications

Updating terminology

Since the inception of this dissertation research, the construct of person-centered/person-directed care has continued to evolve in clinical and scholarly discourse. During this time in the clinical and policy literature, there has been a move away from the term person-centered care to that of person-directed care (e.g., Pioneer Network, Oregon Geriatrics Society, Mather LifeWays Institute on Aging, Centers for Medicare and Medicaid Services, and others) with evidence of the use of this term entering the research literature as well (White, Newton-Curtis, & Lyons, 2008). Critical attributes associated with person-directed care include personhood, comfort care, autonomy and choice, knowing the person, and support for relationships (White et al., 2008). These are identical to those previously discussed as attributes of person-centered care, though autonomy and choice are highlighted. White and colleagues (2008) suggest that "in a person-directed environment, the assumption is that independence enhances competence and that care must be supportive of personal agency. Emphasis is on empowering residents, even those with cognitive impairments, to make their own decisions about their care, schedules, and activities" (p. 115). This new, preferred term carries with it a stronger connotation that the person-receiving care is an active participant in guiding care.

Distinguishing good dementia care and person-centered care

Findings from this dissertation research must be discussed within the broader context of dementia care. Without this discussion, a question remains as to whether good or effective dementia care practices and person-centered interactions are synonymous, potentially threatening the overall usefulness of the study (Ericson, Hellstrom, Lundh, & Nolan, 2001). Practically speaking, if good dementia care practices are being provided, perhaps a sufficient and reasonable level of care has already been reached. Person-centered care is then no longer a necessary aspiration.

Good dementia care is a broad, poorly defined term, but includes those activities, both administrative and clinical, that foster well-being for the person receiving care. Approaches and care practices associated with good dementia care have long-standing advocates and are supported in both the clinical and research literature (Chalmers, 2000; Burgener, Bakas, Murray, Dunahee, & Tossey, 1999). However, there appears to be an assumption within dementia care literature discourse that there is consensus about what constitutes good dementia care. Good dementia care discussion is generally limited to those caregiving practices that are considered effective to either reduce behavioral symptoms or to meet basic needs without eliciting problem behaviors. During caregiving interactions, good dementia care practices represent positive intentions from care providers, including common courtesies (e.g., identifying the caregiver, using the person’s name/title) and information about caregiving tasks, including step by step instruction and explaining procedures before performing them (Burgener, Bakas, Murray, Dunahee, & Tossey, 1998; Kovach, 1997; Hallberg, Holst, & Nordmark, 1995; Chalmers, 2000). The caregiving approach is polite and friendly, using appropriate smiles and soft voice, and may include expressions of interest in the resident’s well-being and demonstrations of kindness and gentleness, through praise and positive responses

(Burgener, et al, 1998, Kovach, 1997; Hallberg, Holst, & Nordmark, 1995; Chalmers, 2000).

However, good dementia care practices and person-centered interactions are not interchangeable. Instead, these good dementia care practices are viewed as an antecedent to the person-centered caregiving interactions described as a result of this study. Good dementia care practices are thus foundational to person-centered care interactions; person-centered care cannot exist separate from good dementia care.

This study sought to parse out those aspects of caregiving interactions which were unique to person-centered care and distinct from good dementia care. This aim, to clarify the boundaries of person-centered caregiving interactions, assumes that all care practices essential to good dementia care are incorporated into the provision of person-centered care at the bedside. This view suggests a continuum of caregiving interactions (Harvath, personal communication, 2009; Misiorski & Rader, 2005) with categories of quality dementia care improving toward a person-centered or person-directed category at the far right end of the continuum. Thus, person-centered caregivers will not only seek guidance, validate satisfaction, clarify ambiguity, negotiate resistance, and adjust care, they will be polite, considerate, and provide step by step instructions through tasks, all of which are necessary aspects of good dementia care. Additionally, caregiving cannot be considered person-centered unless other clinical caregiving issues such as proper positioning or hygiene (e.g. hand washing prior to starting care, gloving during incontinence care), fundamental aspects of dementia care, are of equally high caliber.

Comparison of study findings and literature addressing good dementia care. Several of the practices and strategies identified as good or effective dementia care in the research literature were supported by the current study (Burgener, et al., 1998; Chalmers, 2000; Kovach, & Meyer-Arnold, 1997; Hallberg, Holst, Nordmark, et al, 1995). These practices generally validate the eight nonverbal principles identified in the present research. More specifically, the results related to caregiver nonverbal interaction principles determined to be critical to the provision of person-centered care in this study (e.g., volume and rate of speech reflect the patient's needs, adjusting pace of care to latencies in cognitive processing) extend this previous work. This is significant in that it provides descriptive clarity to the previously unanswered question of what person-centered care looks like during caregiving interactions.

This study found that person-centered care is more than those nonverbal behaviors identified in previous research (Burgener, et al., 1998; Ridder, 1985; Roberts & Algase, 1988). While those nonverbal aspects of the interaction are critical to whether the verbal content of an interaction is person-centered or not, they do not stand alone as person-centered care. Person-centered care requires an active, continual process of seeking guidance, clarifying ambiguity, validating satisfaction, and adjusting care based on the feedback from the person with dementia. It was these interactive behaviors that were key findings from the current study.

Caregiving interactions are not only made up of the verbal and nonverbal actions of the caregiver, they also include complex cognitive processes. While this study did not directly address this aspect of the process of care delivery, it did not go without consideration. Caregiver cognitive processes are important because they begin to attend to the question of intention and motive of the caregiver. Janes, Sidani, Cott, and Rappolt (2008) addressed this in their qualitative study with caregivers of people with dementia in which they explored the process by which caregivers practice person-centered care. The authors proposed a theory of ‘figuring it out in the moment’ to conceptualize the resulting process. ‘Figuring it out’ refers to the process of decision-making that caregivers employ during hands-on care, influenced by qualities of the care recipient, and relational qualities within facility milieu, knowledge, experience and personality traits of the caregiver.

Findings from Janes and colleagues study suggested four phases of decision making. One phase, particularly relevant to the current study, is a melding or informational gathering phase. Caregivers reported using other team members, experience, and resident observation as their main sources of information for providing care. Only five of the twenty caregivers interviewed voiced using resident report as a primary source of information for the provision of person-centered care, contrasting the results of the current study. Instead, caregivers reported using a perspective of ‘if it were me’, with one caregiver expressing this perspective by saying, “…you put a lot of your own personality and your personal beliefs … on to another person” (p. 16). The findings from the Janes et al. study (2008) suggest that even when caregivers intend to provide person-centered care, they predominately provide care as they believe best rather than truly focusing on soliciting the immediate needs, preferences, and wishes of the person receiving care. Thus, simply asking caregivers about the cognitive processes they use when providing perceived person-centered care may not reveal what caregiving actions actually make up person-centered care.

Of interest to the current study was the finding in Janes et al.'s study (2008) that there was no direct link between a caregiver knowing what should be done and actually doing it in actual caregiving episodes. Instead, caregivers experience a significant amount of stress during hands-on caregiving requiring rapid decision making to avoid escalating a resident's behavioral symptoms. This suggests that many caregivers do not have confidence in their skills to effectively negotiate resistance and behavioral symptoms, an area identified as unique to person-centered caregiving interactions. Perhaps because much of person-centered care training has been conceptual rather than practical, as the findings of this research offer, caregivers remain in a deficit with regard to person-centered caregiving interaction strategies.

Proposed Modification to the Conceptualization of Person-Centered Care

The findings of this study establish a new understanding of person-centered caregiving interactions and at the same time inform the broader construct of person-centered care. There is some beginning agreement that person-centered care has at least three critical attributes: 1) knowing the person, 2) fostering relationship, and 3) providing a supportive environment. The attribute of knowing the person is specifically addressed by the findings of this study and modifications are suggested. No modifications are proposed to the other two attributes, fostering relationship and providing a supportive environment based on the findings of this study.

Modification to knowing the person. Because the focus of this study is on caregiving interactions, the findings from this study are most relevant to the attribute of knowing the person. The commonly accepted definition of knowing the person is of value to the overall concept of person-centered care. Knowing the person has been understood as the caregiver's knowledge of the care receiver's premorbid personality, dementia-related disabilities, and common responses to various situations. (Evans, 1996, Harvath, 1990). Unfortunately, the application of this attribute has constricted this particular way of *knowing* to knowledge of past personal, medical, and social history. This has most often been a static way of knowing as reflected in a formal care plan or a one-page biography posted on the wall in a resident's room as opposed to a dynamic knowing that is evident/unfolds during caregiving interactions.

As defined and applied, the attribute of knowing the person has much value. Astute caregivers use this way of knowing to learn about aspects of care that are imperative to positive and successful caregiving interactions. This has previously been referred to as 'local knowledge,' reflecting the unique information a caregiver has about each person for whom they care (Harvath, 1994). By working with a person with dementia over time, this accumulated knowledge can aid caregivers during hands-on care. Local knowledge may enhance the caregiver's understanding of the meaning of behaviors or provide a basis for asking questions of the person with dementia.

In this study, two codes in the subcategory of seeking guidance reflect the importance of this kind of local knowledge that can develop with time and relationship. These were a) asking about preferences and b) asking about comfort and pain. Asking about preferences can be done in a general way, when prior knowledge is unavailable, or more specifically, when something about previous preferences is known. For example, a caregiver may say something like, "You always look beautiful with your lipstick on. Would you like to wear lipstick today?" However, once the caregiver begins to assume that the person with dementia will always want lipstick, the caregiver has moved toward a more static, assumption-based knowing and away from person-centered care. In the code ‘asking about comfort and pain’, the caregiver may use previous knowledge to identify a known painful body part, allowing the caregiver to more specifically address potential pain. For example, before assisting a resident with a transfer out of bed, the caregiver may say, “That right knee often bothers you. Is it hurting today?” This kind of prior knowledge is valuable and likely adds to the degree of person-centeredness in each episode of care.

At the same time, based on the findings from this study, a more precise and active term appears to better reflect the important attribute of knowing the person. Refinement of the knowing the person attribute is developed based on the subcategory results of Seeking Guidance. Seeking guidance, as described in this study, provides concrete evidence of knowing the person in the immediate, in-the-moment knowing that is required for hands-on caregiving. To fully capture the essence of knowing the person, in-the-moment knowing must be included if we are to move beyond a fixed understanding of the person to whom care is being provided. The person-centered interactions identified in this study are the result of an ongoing, dynamic process which reflects more accurately those interactions to person-centered care at both the macro and micro-levels.

Thus, the term seeking to know the person is proposed as a more accurate descriptor, improving the precision of the previously accepted term**.** Seeking to know as a critical attribute connotes an active, ongoing desire for understanding of the other (the care recipient) and suggests an internal attitude which recognizes the inability to truly know another person. In other words, knowing is not something that can be accomplished; it is a striving after. Caregivers must hold an internal stance that recognizes what they do not know in any given caregiving moment, despite the fact they may have cared for this person for several months or even years. This awareness of what is not known drives the caregiver to seek guidance in the moment of care delivery. It is what drives them to look for cues, to ask about preferences during the immediate episode of care, to ask about comfort in this moment, to ask about readiness for the task at hand, and to ask for feedback, all of which were observed descriptors of this category of seeking guidance. The inability to truly know a person is, at least in part, a result of those transient factors that cannot be known at the beginning of each episode of care (e.g., the care receiver's mood, interpretation of events, fatigue, acute illness, changes associated with subtle cognitive deterioration, or variations within normal human behavior).

Care that lacks caregiver interactions that seek to know the person receiving care risks becoming stagnant and is no longer person-centered, because care that relies on caregiver assumptions of preferences or satisfaction is at best centered on some previous static 'knowing'. Recent studies of caregiver perspectives during caregiving suggest that caregivers require new ways to approach each caregiving episode. Not only do they benefit from new skills, but also from new ways of thinking about their attitudes toward the care they provide. Without this, caregivers may approach care with an 'if it were me' perspective (Janes et al., 2008), which leads caregiver-centered care rather than person-centered caregiving. A caregiver-centered approach was similarly identified by Sharpp (2009) and Misiorski and Rader (2005). Other caregivers may address care by thinking of the person with dementia as fictive kin (Fisher & Whallhagen, 2008), or similar to their own child (Anderson et al., 2005), leading to care that may not value the uniqueness and individuality of each person receiving care.

Without the active process of seeking guidance, which is essentially the act of seeking to know the person's preferences and needs in the moment of care delivery, caregivers are at risk of providing care based on their assumptions and interpretations, however well-informed or well-intentioned those assumptions may be. Assuming that preferences and needs are static undermines the value within the broader person-centered care construct that honors the uniqueness and humanity of each individual.

Measurement Implications

The contextually based understanding of the components integral to person-centered caregiving can serve as a beginning platform for an observational measure of the 'person-centeredness' of caregiving interactions. Current measures of the person-centered care remain at a high level of abstraction, often measuring aspects of the construct within systems of care, such as in the White and Lyons (2008) tool, the Person-Directed Care Measurement Tool. Other tools are survey reports from caregivers (Chappell et al., 2006; Bamford et al., 2009) that attempt to measure caregiver knowledge of important aspects of person-centered care, but do not capture whether that knowledge is transferred to caregiving interactions or resident outcomes. Finally, Edvardsson and colleagues (2009) have developed and tested a resident questionnaire that seeks to measure whether the climate of care within a given institution is perceived as person-centered, but does not evaluate whether caregiving interactions are person-centered. There is thus a need for a reliable and valid instrument to measure person-centered care delivery through caregiving interactions, in that the caregiving tasks have a significant impact on a resident's quality of life and overall quality of care.

An important next step in person-centered research is the development of a coding scheme using the discreet, independently person-centered interactions that were the predominant findings of this study. While one occurrence of a person-centered interaction does not constitute person-centered care, arguably a string of these person-centered interactions would enhance the person-centeredness of the overall episode. An observational checklist for coding these behaviors is one approach to beginning measurement based on the study findings. Another alternative is based on the logic that care episodes with a higher percentage of single person-centered interactions would reflect a higher degree of person-centered care. In either case, it could be argued that the subcategories of Seeking Guidance and Adjusting Care should be weighted more heavily due to the critical nature of these aspects of person-centered caregiving interactions. This foundation is a valuable contribution to nursing science given the lack of tools to precisely measure this important construct at the caregiving level.

Clinical Implications

In general, the findings from this dissertation research are significant for their immediate clinical application. They are ready-made for teaching purposes and have the potential to directly change care practices. The results of the study are parsimonious and yet reflect complex human interactions. Using the conceptual diagram and descriptive definitions, a nurse educator or nurse supervisor could introduce these important concepts to CNA caregivers to improve person-centered care delivery. When caregivers are given the knowledge gained from this study, they are in a position to immediately provide person-centered care during each caregiving interaction. Knowledge of the findings from this study, combined with the internal drive that most caregivers maintain to excel in their work, can readily increase person-centered interactions in nursing homes today.

This observation, that it is in the hands of each individual caregiver to provide person-centered care during hands on care, is critical to both the clinical application and broader theoretical construct of person-centered care. Efforts to transition nursing homes from the traditional, institutional model of care to one that is intentionally guided by the people living in the nursing home have primarily been implemented in a top-down fashion. This has been done to address the important impact of decisions made at an administrative level and is valuable in transforming an entire facility. However, approaching the adoption of a new philosophy of care in this way may lead to a perception by direct care staff, nurses, and CNA caregivers that they are not in a position to effect change until the administration is supportive and leading an effort to transform the facility. The findings of this study suggest that caregivers are in a much stronger position and can indeed begin transforming their caregiving interactions toward person-centeredness, independent of the stage of change in the rest of the facility.

Response to consultant feedback

Additional discussion of clinical implications is guided by the valuable feedback from clinical expert consultants during the analysis phase of this study. Both consultants raised similar practical and relevant concerns about the findings of the study. First, Joanne Rader’s concern addressed the aspect of the resulting model that suggests caregivers must continually ask permission, a strategy identified in the Seeking Guidance subcategory. Second, Lynn Szender’s concern focused on caregivers who do ask permission but repeatedly receive a ‘no’ response from the person, resulting in unaccomplished tasks.

Following the discussion of these two issues, the question of whether person-centered or person-directed care can be provided to the person with dementia who is no longer able to respond will be addressed. Finally, the discussion will conclude with an overview of implementation strategies for improving care based on the findings of this study.

Joanne Rader, RN, MN, FAAN, a nationally recognized clinical nurse expert in the topic area, offered critique of what she called ‘digging yourself into a permission-asking hole’. By this, she referenced the asking permission strategy within the Seeking Guidance subcategory. This strategy carries the definition: “Before initiating any care activity that requires hands-on assistance from the caregiver, the caregiver asks the person receiving care if he/she is ready to begin the process”. Clinical experience suggests that if caregivers ask permission before initiating care tasks, the person receiving care may say no, creating situations throughout the caregiving episode that may hinder task completion.

Ultimately, this concern has ethical and theoretical implications as well as clinical ones. Caregivers who choose not to ask for permission in order to avoid a refusal from the person receiving care move away from being person-centered and toward a caregiver-centered approach. In these cases, autonomy and choice have been removed from the caregiving and replaced with care that is guided by efficiency concerns. Autonomy and choice are continually at risk of being lost as dependency increases. It is therefore essential that caregivers ask for permission at two critical points during care. These are 1) at the beginning of care to assess readiness to start the process of getting ready for the day, and 2) at the conclusion to a negotiation process before initiating care again. Avoiding asking for permission at least at these two events places more value on completing the task than on the autonomy and choice for the person, and the care is no longer person-centered. In fact, it would be in those cases that care has returned to a more efficiency driven model.

When person-centered care ideals are valued over the completion of a task, the question of ‘digging yourself into a permission-asking hole’ is less important. However, suggesting the question is no longer relevant when fully embracing person-centered care ideals does not ignore the complexity of situations that arise in caregiving, nor does it minimize the great need for creative, practical solutions for caregivers. Caregivers continue to need strategies to successfully and artfully balance caregiving tasks, but task completion should not take priority over the person’s autonomy and dignity. Asking permission must move beyond a simple, “Are you ready to get up?” to something more positive and encouraging, such as, “I hear they have pancakes for breakfast, can I help you get ready to go?” It is most important, though, to be mindful of the values and ideals critical to person-centered caregiving interactions, so as to not revert back to previous ways of caring.

Lynn Szender, RN, a locally recognized clinical nurse expert and nursing home administrator also raised a similar concern about caregivers who use a refusal from the person receiving care as an excuse not to complete the person’s care needs. This is a variation to the previous concern and the responses above are applicable. Additionally, this issue is also addressed in the subcategory of <u>negotiating resistance</u>. In this process, one hallmark of person-centered negotiation was that of <u>accepting resistance</u>, defined as verbally acknowledging and validating the resistance of the person receiving care. For example, the caregiver asks the resident if he is ready to get out of bed. He responds with a rather gruff “No.” Instead of cajoling or urging, as seen in other clips, the caregiver simply offers an accepting “Ok” and stops any further movement toward the task. Within this interaction strategy, the caregiver creates an environment of non-resistance, choosing to meet resistance with acceptance rather than with more resistance

Observation of this particular interaction and similar ones are evidence of a person-centered approach because caregivers are deferring to the person receiving care. This is actually beneficial to both members of the caregiving dyad. Caregiver deference in the face of resistance benefits the care receiver in that it rapidly eliminates escalation of the resistance, and decreases the amount of time spent in resistance, which is presumably in response to a negative event as perceived by the person with dementia. It is beneficial for the caregiver for the same reasons; caregivers often experience resident resistance as stressful and negative (Janes, Sidani, Cott, & Rappolt, 2008). Furthermore, once resistance is recognized, avoiding further resistance is an active way for the caregiver to communicate that the person receiving care is leading the process, a hallmark of person-centered caregiving interactions.

Person-centered caregivers learn to skillfully negotiate through resistance through the use of the strategies identified in the study. In doing so, they are able to reframe an initial refusal or non-cooperation into a situation that maintains the balance of autonomy and task completion. This real tension that exists frequently in caregiving for the person with dementia is ameliorated somewhat by offering choices (offering a plan B) that provides control while moving the progress of prioritized tasks ahead. For example, in the situation referenced previously, after the caregiver accepted resistance with her simple “OK”, she then offered a suggestion that the two of them together “give it a few more minutes”. She stayed by his side, gently massaging the gentleman’s knee, quietly allowing time to pass before approaching the task again. When she did, he was cooperative and demonstrated readiness for getting out of bed.

Further, this commonly voiced critique raised by Lynn Szender, RN of the practicality of person-centered care ideals, is often expressed by nurses, and all too often deters the implementation of person-centered care practices. Underlying the question raised by Lynn Szender is the larger debate about defining ‘the person’s care needs’. Determining and prioritizing these needs: what they are, how often they are addressed, how they are addressed, and when they are addressed, is largely the purview of the nurse in the nursing home. As a result of this traditionally held decision-making role, nursing home nurses are in a position to facilitate or hinder person-centered care practices at the bedside. In many cases, it is not the CNA caregiver making excuses to avoid caregiving; it is the nurse who is being challenged to think creatively, to be willing to alter routines and schedules, to reassess care priorities so that they are aligned with the preferences of the person needing care.

Nurses have been challenged for more than a decade to move away from rigid task oriented schedules toward flexibility based on the resident’s needs and preferences (Kovach & Meyer-Arnold, 1997). In the case of a caregiver who is struggling to negotiate successfully through a caregiving issue, the nurse again plays the pivotal role in providing leadership in managing difficult clinical situations. For the nurse, this starts with a firm understanding of and commitment to person-centered ideals, ownership of the responsibility to be a facilitator of person-centered care practices, and a willingness to invest in relationships with caregivers (Anderson et al., 2004), observing their practices and supporting their developing skills . These ideals are strongly advocated by the Pioneer Network, an organization dedicated to the transformation of nursing home culture (Fagan, 2003; Lustbader, 2001).

Verbal communication capacity and person-centered dementia care

The practical issues of providing person-centered care raise several other important clinical application and relevance questions. In this study, the subcategory of <u>Seeking Guidance</u> is considered essential to person-centered care interactions. Outside of the strategy of <u>looking for cues</u>, person-centered interactions require asking questions of the person with dementia. This logically leads to a concern about the person with severe or late-stage dementia that is no longer able to respond verbally. A similar issue arises with the person who expresses a verbal response that is incongruent with their behavioral response. For example, if a caregiver asks about whether the person is comfortable and the person responds ‘yes’, but they are restless and frequently changing position in bed, there is incongruence between verbal and behavioral responses. The dilemma becomes one of acting on the persons words or acting on the person’s behaviors.

To address the question of whether person-centered care is operationalized in the same way for a person with dementia that appears no longer able to guide care through verbal means involves two lines of thought. First, there are anecdotal reports of people previously considered ‘nonverbal’ who showed a capacity for a verbal response when caregiving was provided with sufficient positive regard through a meaningful relationship. This kind of relationship building is predicated on consistent assignments so that caregivers are able to care for the same person day in and day out. The use of the person-centered caregiving interactions that were identified as a result of this study enhance opportunities for caregivers to foster this verbal capacity in residents previously thought to be nonverbal. By observation, often times caregiving for the person with dementia is provided in near silence. Educating caregivers about concrete questions they can ask not only serves to gather information for adjusting care, but also provides relevant, meaningful conversation that communicates interest in and a value for the person receiving care. Consistent assignments in conjunction with consistent use of person-centered caregiving interactions aids in maintaining personhood, communicates a message of interest and the concept of ‘seeking to know the person’ remains central. Ultimately, we return to the idea that assumptions must be avoided. In this case, health care providers need to move away from assuming nonverbal status; caregivers should always be communicating as if a verbal response is possible and desired.

Second, if verbal responses sufficient to guide care are no longer possible, this raises a question of whether person-centered care is possible for this population. Findings from this study suggest the care recipient’s response (guidance) is an essential aspect of person-centered caregiving interactions in order that care can be adjusted toward those responses. When that critical link in the interaction process is broken, person-centered care, as conceptualized in this study, is no longer possible. The argument is stronger if the newly preferred term ‘person-directed’ care is used. This is true because caregiving is then provided based on caregiver interpretations of satisfaction and assumptions about needs and preferences. If caregiving interactions can no longer be directed by the person, it ceases to be person-directed care.

This argument is not to suggest in any way that care for this person becomes poor care. The argument is simply made in an effort to be precise in our terminology, intellectually honest, and conceptually consistent. If one critical attribute of a construct is lacking, the construct is no longer fully represented. In this case, caregivers are unable to fully offer autonomy and choice, although preferences might still be able to be inferred. Care for the person with dementia who is no longer able to guide care can be exemplary dementia care; it can be gentle, attentive and responsive to any behavioral cues, it can maintain personhood through ongoing attempts at communication and touch, but it cannot be person-directed as conceptualized in this study. It is proposed that it is in this way that person-centered care is distinguished from person-directed care (Harvath, personal communication, 2010). In the absence of the ability to direct care through verbal responses, caregivers must rely on the interpretation of attempted responses or behaviors, when those become the primary mode of communication.

Proposed strategies for enhancing implementation of person-centered caregiving interactions

Avoiding caregiver drift. Person-centered caregiving interactions are complex for people with any level of dementia. The investigator noted during observations that caregivers are capable of providing interactions that are not person-centered and interactions that are person-centered within the same episode of care, recognizing the difficulty of consistently providing this level of high-quality dementia care. Recommending the use of person-centered caregiving interactions as identified in this study has clinical implications for CNAs who may find it challenging to maintain the required interactions. To address this concern, the investigator hypothesizes that the person-centeredness of care episodes would be enhanced if caregivers were free to take breaks during caregiving. To do so may help avoid ‘caregiver drift’, a concept akin to rater or observer drift in research terminology in which attention to detail drops off over time due to mental fatigue or strain. In this intense approach to caregiving in which interactions rest largely with the caregiver, the required mental energy toward person-centeredness can be significant and lead to fatigue or drift away from the process of person centered caregiving interaction. For some dyads, the interactions leading to caregiver drift may come after only one task or even a portion of one task. Facilities would do well to allow caregivers to gauge how much care they are able to provide and remain person-centered, at which time a break would be taken. The caregiver could work with another person with dementia who has different interaction needs and come back to complete any additional care needs for the person where drift was occurring. Supporting caregivers in providing person-centered care in this way would place less demand on either member of the care dyad by decreasing the concentration of tasks and reducing potentially stressful contacts.

Matching caregiver and person with dementia. During observation of the different care dyads in this study, the variation in personality of both the caregiver and the person with dementia was evident. While this was not specifically addressed as a research question, the observation did give rise to additional clinical implications of implementing person-centered interactions. In particular, there may be a benefit to identifying categories of care, based on caregiver style and personality. A questionnaire could be given during an initial assessment for any kind of professional caregiving that would ask, “When it comes to the context of how care is delivered, what is important to you at this stage of your life?” A corresponding questionnaire could be given to CNAs to determine their tendencies in approach and caregiving style. Care assignments could then be considered based on a match between the care receiver’s preference and the caregiver’s style. For example, some care receivers may appreciate banter and humor over tender and nurturing caregiving styles. Others may value a more professional or formal relationship from their caregivers instead of a chatty or overtly friendly approach. To assume that all care receivers want the same approach and style of caregiving is to remove the uniqueness of each individual from the caregiving context. Within these variations in caregiving style, person-centered interactions as identified in this study remain central.

Future Research Needs

Because of the aforementioned study limitations as well as the ongoing development of thought in the area of person-centered caregiving, future research is crucial to further address conceptual issues, measurement of the concepts, and implementation into practice.

Related to this study, further research is needed to validate and extend the comprehensiveness of the findings. Research that allows for caregiver interviews to obtain descriptive data from their point of view about what is person-centered in their caregiving interactions is essential. Equally, if not more importantly, resident-participant interviews are also recommended to gather perceptions of person-centeredness in caregiving. Several questions remain unanswered that could be addressed in these ways. Do the findings of this study correspond to how caregivers understand person-centered care? Do the findings of this study correspond to how care receivers experience person-centered care, or what they expect as person-centered caregiving? From the care receiver’s perspective, what aspects of person-centered caregiving are critical?

Addressing these questions would enhance our understanding of person-centered care at the level of the care dyad, enriched through inductive theory building.

Additionally, studies that aim to clarify the conceptual boundaries of knowing the person, getting at the fine line of static knowing and the dynamic seeking to know would also bring greater understanding to the broader construct of person-centered care. Seeking to answer the questions, how do caregivers use prior knowledge in care delivery? or, is there a point at which prior knowledge hinders person-centered care? would be valuable in offering additional clarification about this important attribute. Finally, future studies that aim to answer whether person-centered, or person-directed care is provided differently based on the level of dementia, or level of communication deficit would also be valuable, both theoretically and clinically. This question aims to deepen our knowledge regarding the practical application issues associated with person-centered caregiving for the person with dementia and is essential for a comprehensive understanding of the topic.

Research aimed at developing measures of person-centered caregiving is also needed. Research tools to capture both treatment fidelity and treatment outcomes would be valuable to nursing science as person-centered care ideals continue to be promoted. Additionally, as consumer advocacy groups and government agencies increase their expectations of person-centered or person-directed in nursing homes, clinically useful tools will be essential to evaluating progress in this area.

The possibility of using the results from this study to teach caregivers the process of person-centered caregiving is a potentially significant outcome. As such, the practically and clinically relevant findings from this study serve as a valuable foundation for future intervention research. Some outcomes that could be hypothesized as associated with person-centered caregiving interactions are 1) a reduction in behavioral symptoms during caregiving, 2) reduced time in caregiving for the person with dementia who is often non-cooperative, 3) increased positive communication within the care dyad, 4) improved quality of life for the person with dementia, and 5) improved job satisfaction for the caregiver. Addressing these unanswered questions would further the knowledge base on the important but under-studied concept of person-centered caregiving.

Summary

Through inductive observation and analysis, the investigator in this dissertation research sought to operationalize person-centered caregiving interactions as they occur during dementia caregiving in nursing homes. Defining the key actions associated with person-centered caregiving for persons with dementia is vital for improving the quality of care and quality of life for this vulnerable and institutionalized population. Ultimately, the conclusions of this study suggest that person-centered caregiving is an ongoing, active process that addresses the immediate needs, preferences, and wishes of the person with dementia during a single episode of care. Throughout each caregiving episode, person-centered caregivers continually seek guidance, clarify ambiguity, validate satisfaction, and negotiate resistance. They do so in a way that respects the individuality of the person with dementia through nonverbal interactions that honor the uniqueness of the individual. These active processes are done so that care can be adjusted to best meet the identified requests of the individual person with dementia. When this level of care is provided, people with dementia maintain dignity and are valued as the sentient adults that they are.

The conceptual clarity resulting from this study has important theoretical and clinical implications. Person-centered caregiving interactions are complex but possible. These ways of caring that honor and value the person, above the task at hand or needs for efficiency, are essential to improving the quality of life for people with dementia.

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Appendix A. Guiding definitions and assumptions

Assumption	**Discussion**	**Literature Support**
Person-centered care can generally be defined as health care that emphasizes the individual needs, priorities, and preferences of patients over those of health care team members or institutions.	This definition serves as a general guide for the study.	Gerteis, Edgman-Levitan, Daley & Delbanco, 2002; Laine, Davidoff, 1996
At the molar level, a critical attribute of the philosophy of person-centered care is <u>knowing the person</u>.	This refers to aspects of care that respect the uniqueness of the individual. Fundamental to this is the belief that disease-related or age-related changes do not diminish, in any way, the uniqueness or humanity of the person. <u>Knowing the person</u> has been defined as "striving to understand an event as it has meaning in the life of the other. It includes avoiding assumptions, centering on the one being cared for, assessing thoroughly, seeking cues, and engaging the self of both" (Evans, 1996, p. 19). The result of this 'knowing' will be care that is given in a way that it is meaningful to the person (Swafford, 2003).	Boettcher, Kemeny, DeShon, & Stevens, 2004; Brooker, 2004; Evans, 1996; Finnema, Droes, & Van Tilburg, 2000; Happ, Williams, Strumpf, & Burger, 1996; Kitwood 1997; Rader, 1995; Rantz & Flesner, 2004; Swafford, 2003; Talerico, O'Brien & Swafford, 2003; White, Newton-Curtis & Lyons, 2007
At the molar level, a critical attribute of the philosophy of person-centered care is <u>relationship</u>.	As an attribute of person-centered care, <u>relationship</u> is generally defined as consistent, trusting, and empathic social interaction that contributes to a positive social environment. It is promoted through consistent and recurring caregiving for the same individual that creates the opportunity for development of both the knowledge and the interpersonal relationship that enhances care. This core value incorporates the intentional 'therapeutic use of self' (Athlin & Norberg, 1999) which is the ability of the caregiver to offer more than a mechanistic act of	Athlin & Norberg, 1999; Boettcher, Kemeny, DeShon, & Stevens, 2004; Brooker, 2004; Evans, 1996; Finnema, Droes, & Van Tilburg, 2000; Happ, Williams, Strumpf, & Burger, 1996; Meleis, 2006; Rader, 1995; Talerico, O'Brien & Swafford, 2003; White, Newton-Curtis & Lyons, 2007

	care by developing a relationship with the person being cared for, shifting toward caring acts that are humanistic in nature.	
At the molar level, a critical attribute of the philosophy of person-centered care is a supportive environment.	Care cannot be truly person-centered unless the physical, social and emotional environment is supportive in a way that adjusts or fits to meet the individuals' needs and preferences. Underlying this attribute is the belief that person-centered care facilitates freedom of choice and maximum control over one's environment. In this way, a supportive environment is one which encompasses the attributes of choice and autonomy (Bamford et al., 2008, Happ, Williams, Strumpf, & Burger, 1996, Kane 2003; Kilhgren, Hallgren, Norberg, & Karlsson, 1994; Sharpp, 2009, Talerico, O'Brien, and Swafford, 2003, and White, Newton-Curtis, and Lyons, 2007.	Hoeffer et al, 2006; Kitwood, 1997; Swafford, 2003; Talerico, O'Brien &; White, 2005.
All behavior has meaning and is useful for guiding caregiving responses.	Underlying this core assumption is the belief that while verbal communication capacity may deteriorate, the person with dementia retains some capacity for communication through the use of verbalizations, vocalizations, facial expressions, and physical actions.	Kolanowski, 2000; Whall & Kolanowski, 2004
The role of the caregiver is particularly salient when interactions involve a person with dementia.	By nature of the losses in memory, executive function and communication abilities, the person with dementia is at risk of being objectified or dehumanized during care, often because expected social interaction patterns no longer apply. To minimize this risk, the caregiver carries the responsibility for the effectiveness of interactions based on their actions and responses. This requires unique skills of the caregiver, who must be attentive to the needs and preferences that are being communicated during caregiving interactions.	Athlin & Norberg, 1987; Eckman, 1991; Kitwood, 1990

Needs, preferences and goals that are more dynamic, such as those encountered during immediate episodes of caregiving are related to one's mood, interpretation of events, fatigue, acute illness, or changes associated with subtle cognitive deterioration.	These needs would be included under the umbrella term, 'proximal factors', in the Need-Driven Dementia-Compromised Behavior Model. These needs may change from caregiving episode to caregiving episode, which make them difficult to address through formal care planning. Person-centered care, at the most molecular level, seeks to meet these immediate and dynamic needs as well as those addressed through care planning.	Algase et al, 1996
The body of literature on person-centered care at both molar and molecular levels provides a meaningful foundation for the proposed study and collectively serves as provisional guide in analysis of the data.	Provisional codes: Responsiveness Recognition Facilitation Negotiation Collaboration Asking for feedback Pacing procedures Pacing speech Responding to need-driven behaviors Using unique details of resident's lives Respecting individuality Encouraging independence	Model of Interaction During Feeding Persons With Severe Dementia (Athlin & Norberg, 1997) Positive Person Work (Kitwood, 1997) Health professional-geriatric patient interaction behavior rating code (Adelson, Nasti, Sprafkin, Marinelli, Primavera, and Gorman, 1987) On-the-job performance measures of person-centered care, Boettcher, Kemeny, DeShon, & Stevens

Appendix B. Caregiver verbal interaction code list after code reduction

CATEGORY & DEFINITION	**CODE**	**CODE DEFINTION**	**ASSOCIATED TRANSCRIPT OF EXEMPLAR VIDEO SEGMENT**
DIMENSION I: Caregiver verbal content independent of resident			
Apologizing Within the verbal content, the CG acknowledges some fault or offense, with an expression of remorse for it.			
	Acknowledging mistake	CG expresses awareness of having made a mistake that affected the resident negatively. (2 clips with this code)	CG: “Whoops, ok. Ok, why don’t you hold on; I’ll pull this up.” (see clip 514-3-19)
Asking Questions A description of any verbal content from a CG that is in the form of a question to the resident.			
	Asking about basic needs	Caregiver asks resident if he/she is hungry, thirsty, tired, cold, or needing to toilet. (3 clips with this code)	CG: “There we go. There, Elsa. You ready for breakfast, hmmm? You hungry?” (see clip 545-5-21)
	Asking about likes/dislikes	Asking resident, in a yes/no manner, about their like or dislike of an object or whether they would like an article of clothing. (5 clips with this code)	CG: “See, got a pretty purple one. You like purple?” (534-5-10)
	Asking about	Either as a course of interaction or	CG: “Am I hurting you, Elsa?

	pain	in response to some indication by the participant, CG asks resident about the specific issue of pain or otherwise expresses concern that the resident is physically ‘ok’. (4 clips)	Elsa, are you ok? Are you ok?” (545-5-10)
	Asking about well-being	CG asks, often in a polite and conventional manner, ‘how are you today?’ or ‘did you sleep well?’ (1 clip)	CG: “How are you this morning, Caroline? Hmmm?” (534-5-5)
	Asking again for a response	A follow up from an initial question that the resident hasn't answered. May be as simple as ‘hmmm?’ or ‘huh?’ or it may involve repeating a portion of the question, or repeating the question in its entirety. (13 clips)	CG: “You want your hat on? … Huh?” (514-4-34)
	Asking for confirmation about CG’s perception	Asks a question in which the CG’s perception about the situation is offered. The resident need only to confirm the perception, and there seems to be an assumption that the resident will say ‘yes’. For example, after placing a warm towel on the resident, the CG asks, "Doesn't it feel good to have that warm towel on you?" (7 clips)	CG: “Isn’t this warm? Doesn’t it feel good to put that warm blanket on there?” (514-4-1)
	Asking for feedback about	CG specifically asks resident for input about the process of care	CG: “How’s that, *resident’s name*, ok?”

	care	delivery. Often takes the form of "how was that?" or "ok?" or 'How's that feel?" (8 clips)	(543-2-16)
	Asking if resident has completed task	Asking if the resident is done with an independent activity (e.g. urinating, washing hands). (3 clips)	CG: "*Resident's name?* Are you done with the urinal?" (514-4-16)
	Asking if resident is able and willing to perform an action	By way of a question of ability (i.e., Can you bend your knee?) CG prompts resident to assist/facilitate the care process by doing something or moving to a different position. (6 clips)	CG: "Can you bend your knee? There." (514-4-6)
	Asking resident for assistance with an activity	CG asks resident to help in some way with the completion of the activity, (e.g., positioning clothing, holding undergarment in place). (2 clips)	CG: "Can you hold that right there for me?" R: "Yes, I can." (514-2-21)
	Suggesting a choice in participation	By way of a yes/no question, the CG asks the resident for permission, either directly or indirectly, or asks about readiness to move forward with the next activity. Or, CG may place an 'ok?' at the end of information or instruction about the caregiving process/activity. (12 clips)	CG: "Are you ready to go eat?" R: "Yeah." CG: "Alrighty." 543-2-49
Commenting A description of the verbal content of the CG that constitutes a comment and			

is not better described by another category. A comment is generally uni-directional; there is no expectation of a response from the resident.			
	Acknowledging cooperation	Brief comment from CG that makes note of the resident's cooperation. (1 clip)	CG: “I need you to move your hands, guy, …there you go.” 543-2-22
	Commenting about a negative habit	CG says something about a negative habit of the resident. Uni-directional; CG doesn't appear to be expecting a response. (2 clips)	CG: “If you’d only keep your clothes on everyday, huh?” 534-5-8
	Commenting about an object	CG makes a comment about an object (e.g. an article of clothing) that is unrelated to the utility of the object or information about the object 2 clips	CG: “See, got a pretty purple one.” 534-5-10
	Commenting about how positive the activity should feel to the resident	CG expresses either an intent or hope that the resident is experiencing the activity in a positive way. 1 clip	CG: “Here, that should feel real good on your face.” 545-5-1
	Commenting about involuntary actions	CG uses an event such as a yawn by the resident as a topic for a comment, may be unidirectional or could be interpreted to be initiating conversation (1 clip)	CG: “Wow, that’s a big yawn; must be waking you up now, huh?” R: “Yeah.” 543-2-27
	Expressing	CG expresses regret in some	R: “Oh, Jesus, my…”

	regret	manner. May be a quick or passing, 'I'm sorry', that conveys awareness that the resident has little choice in the activities underway, or that the process of care is at times uncomfortable. (2 clips)	CG: "Does that hurt? Does that hurt, *resident's name*?" R: "Yeah." CG: "Yeah? I'm sorry." 543-2-25
	Marking general progress	CG uses very general terms to comment that some progress has been made in the activity at hand, (e.g. 'there', or 'ok') 20 clips	CG: "Ok, I'm going to roll you again. There." 545-5-12
	Rhetorical question	A comment in the form of a question, the CG asks a question, but there's no evidence of desire for or expectation of a response. (2 clips)	CG: "Pillow's not doing you any good, is it?" 543-2-36
Complimenting A description of the verbal content of the CG that takes the form of praise or flattery.			
	Complimenting	A positive comment made to the resident about the resident's physical appearance. (3 clips)	R: "My,…I,… I can't see." CG: "You look good." 514-3-44
Encouraging A description of the verbal content of the CG that takes the form of supportive words that impart confidence or inspiration to the resident.			

	Approving words	CG offers supportive words to resident, usually about activity that is occurring or has just occurred, or as a statement of belief in the resident's ability or capacity to complete a task. (10 clips)	CG: “Ok. That’s good, that’s very good. Here’s a towel, you can, you can dry your face with it. Ok? R: “Oh, that’s a good one, I enjoyed that.” 514-2-32
	Supporting independent activity	CG encourages resident in independently doing the activity by conveying that the CG won’t be doing the activity for the resident. For example, the CG may say to the resident, I’ll let you do that (put on your shirt)’, implying that he/she won’t be doing that. (3 clips)	CG: “Yeah, go ahead, I’ll let you do it. Brush your teeth, ok?” R: “Yeah.” 514-2-27
Explaining The verbal content of the CG seeks to provide a reason the resident is being expected to do the activity at hand.			
	Explaining why	Offering a rationale for the current activity or upcoming action. (22 clips)	CG: “Just undo your legs, sweetie. I’ve got to get you clean, *resident’s name*”. 545-5-5
Extra Terms			
	Terms of endearment	CG uses an endearing term when referring to the resident, such as 'honey' or ‘sweetie’. 15 clips	CG: “Here, let’s take off the covers, bring your legs around, sweetheart.” 534-5-3

	Polite terms	Within the verbal content, CG uses polite terms such as 'please' or 'thank you'. 3 clips	CG: "Ok, sit up on the side of the bed, please." 534-5-1
	Using resident's name	Within the verbal content, the caregiver uses the resident's name. 38 clips	CG: "How was that, *resident's name*?" Pretty good?" R: "You bet." CG: "Ok." 543-2-48
Getting Resident's Attention The verbal content of the CG's speech is used to increase the likelihood that the resident is listening to the CG.			
	Getting resident's attention	Through some verbal means, CG seeks to get resident's attention, often by saying their name before speaking, or saying, "here,..." to hold their attention before providing new information. 14 clips	CG: "Ok. K. Ok. Turn this way, I can help you with that." 514-3-41
	Using an engaging question	Through the use of an engaging question such as, 'you know what?', the CG appears to attempt to shift the topic or focus of activity toward some other task. May be used as a means of distracting a resident who is perseverating. 1 clip	CG: "Ok. You know what?" R: "It's all, yeah, it doesn't go where it belongs." CG: "Ok, why don't we go, let's walk over to the sink so you can wash your hands, and then we'll fix it, ok?" R: "Alright."

			514-3-24
Greeting The verbal content of the caregiver's speech is a traditional greeting to the resident.			
	Good morning	Caregiver greets resident with a formal 'good morning' of some sort. 1 clip	CG: "Ok. I'm going to sit you up, *resident's name.* Get you in your chair. Here we go. Good morning!"
Informing The verbal content of the CG's speech is used to provide information necessary for the task at hand.			
	Informing about an object	Identification of or description of characteristics of an object that facilitates its use. 7 clips	CG: "Here's your watch." R: "Hmmm?" CG: "Your watch, so you know what time it is." 514-3-39
	Informing about the process or activity	Usually uni-directional, CG tells resident some information about the 'what' of present or future activities. Or, CG may tell the resident that he's leaving the room for some purpose. 87 clips	CG: "Ok, I'm going to turn off the water, ok?" R: "Ok." CG: "K." 514-3-35
	Informing the resident about him/herself or	CG makes an observational/informing statement that simply describes something	CG: "Ok, can I brush your hair?" R: "Please."

	action	related to the resident, either a like/dislike, or something about their position, actions, or physical appearance. 4 clips	CG: “Ok, you like that.” 534-5-28
	Informing about timing	CG tells resident about the timing or sequencing of an activity or action. May be announcing immediate or impending activity. 28 clips	R: “I have to pull this up.” CG: “Well, we’re going to have you stand up first and then we’ll pull it up, ok?” 514-3-15
	Informing about what the CG needs from the resident	Stated in an 'I need you to...' phrase, the CG states a need and at the same time informs the resident of what's getting ready to happen. Typically that the CG needs the resident to move in some way in order to finish the task. 3 clips	CG: “Ok, well, I need you to stand up. Here we go. One, two, three, Up. Good job. Turn, turn, turn, and down.” 543-2-46
	Suggesting an activity	Caregiver uses a sentence structure that is suggestive rather than directive, such as, “let’s do this one” or “let’s go to the dining room”. 11 clips	CG: “You want to go to the sink and wash your face, *resident’s name*?” R: (stuttering vocalizations) CG: “Let’s go wash your face over there. You want to?” 534-5-22
Instructing The verbal content of the CG’s speech is used to provide instructions necessary for completing the task at hand.			
	Giving instructions	Instructing or directing resident during care activity in a manner to	CG: “Ok here, you can rinse your mouth, ok. Rinse your

		assist the resident in completing the activity. 64 clips	mouth and then spit it out.” 514-3-34
	Instructing resident to let CG help	CG makes self available for helping resident. Sentence structure may be "let me help you" or "turn this way, I can help you with that"... 2 clips	CG: “There, ok, let me help.” 534-5-21
	Presenting an object	CG presents an object or article of clothing, identifies it and hands it to the resident, expecting resident to take it as it is needed for the next activity or for finishing care. 4 clips	CG: “Ok. Hairbrush?” 514-3-37
	Repeating instruction	Restating the instructions to the resident to reinforce the instruction, restate them in a way that improves understanding, or in response to a question by the resident. 19 clips	CG: “Ok, let’s stand up, pull your briefs up. Let’s stand up, sweetheart.” 534-5-20
Language Usage/Phrasing Description of ‘how’ (not what) information is communicated to the resident.			
	Speaking from the CG perspective	While instructing, speaks from CG point of view, such as, "turn my way" or "I want you to wear this". 6 clips	CG: “There, I got this shirt too, I want to put on. Kind of raining outside today.” 543-2-44
	Using plural pronouns	CG says 'let's', 'we', or 'our' when instructing or giving information to	CG: “Should we pull you over a little closer to the edge?”

		the resident. For example, “We’re going to swing our legs to the edge of the bed.” 64 clips	514-3-5a
	Using formal or technical terms	Describes or names objects using a technical/medical or formal term that the person with dementia may not be familiar with, such as 'Attends' or 'peri-area'. 6 clips	CG: “Ok, *resident’s name*, I’m going to change your attends.” 543-2-21
	Abstract phrases	Caregiver uses fairly abstract phrases that may be difficult for the person with dementia to interpret. For example, “I'm going to get the sleep out of your eyes." 10 clips	CG: “Let’s wash your face, ok? Get the sleep out of your eye.” 534-5-26
Negotiating The verbal content of the speech of the CG communicates the desire to overcome an obstacle by reaching a mutual agreement by way of compromise.			
	Suggesting an alternative	In response to dissent from the resident, the CG offers an alternative plan in order to complete the activity at hand. 4 clips	CG: “Are you ready, *resident’s name*?” R: “No.” CG: “No?” R: “No.” CG: “Ok, well, let’s give it a couple more minutes, then we’ll bring our legs out and get

			in your chair, ok?” 543-2-38
Reassuring The verbal content of the speech of the CG restores a sense of confidence for the resident.			
	Reassuring	CG offers positive words to affirm resident's safety or to instill confidence, usually after the resident has expressed misgivings, distinguishing it from ‘encouraging’. Reassuring, in this sense, is expressed in a fairly concrete way, such as 'it's ok' or 'that’s fine’. 2 clips	CG: “Yeah, go ahead and sit down.” R: “I’m ok?” CG: “Yeah, you’ll be ok.” 514-2-5
DIMENSION II: Caregiver verbal content in response to resident			
Responding to Actions A description of the verbal content of a CG that is specifically in response to an action or behavior by the resident.			
	Affirming resident’s action	CG uses approving words in response to the resident doing some independent activity. In some cases the CG may seem to be 'granting permission' for the activity, as if he/she isn't going to do anything to stop the resident, but the verbal response and phrasing conveys that	CG: “Ok, then I’ll wash it in bed for you. You can lay in your bed while I do this.” 534-5-24

		the CG is in control. 2 clips	
	Checking an interpretation	In response to the resident's actions, the CG seeks to confirm his/her interpretation of the action. 4 clips	CG: “You want some lipstick on? Huh? Is that a ‘no’, *resident’s name*?” 534-5-30
	Giving additional instruction	In response to the resident's actions, CG offers additional instruction. This will also be captured under the category heading: ‘Instructing' 8 clips	CG: “Wait, before you stand up, let me raise your bed up a little bit.” 514-3-16
	Instructing resident to let CG help	In response to resident's actions/behaviors, CG offers help. This may be appropriate, if the resident is having difficulty, or inappropriate, if the resident is independent but the CG desires to assist for expediency. 1 clip	CG: “Ok. K. Ok. Turn this way, I can help you with that.” 514-3-41
	Interpreting assent to proposed activity	Based on activity, lack of activity, or posture, CG interprets resident's behavior as assenting to the proposed task. 1 clip	CG: “Let’s wash your face, ok? Get the sleep out of your eye.” 534-5-26
	Interpreting dissent or completion of activity	CG interprets behavior of resident as communicating that the resident is declining the proposed activity or is 'done' with the activity underway. 5 clips	CG: “Are you sure you don’t want to come down to the dining room?... Ok, I’ll bring your breakfast into you…” 534-5-32
	No response	When an independent action, separate from completing a caregiving task is initiated by the resident, the CG offers no verbal	CG: “How was that, *resident’s name*?” Pretty good?” R: “You bet.” CG: “Ok.”

		response. 3 clips	Note: video viewing is critical with this exemplar since it is a ‘no response’ code. 543-2-48
	Stating CG response	In response to the resident’s actions/behaviors, CG tells the resident what he/she will do. 5 clips	CG: “I’ll fix this. R: “Can you get that?” CG: “Yeah, I’ll come back and fix it.” 514-3-47
Responding to resident’s verbalization or activity A description of the verbal content of the CG’s speech specifically in response to the resident’s verbalization or vocalization (non-intelligible vocal utterance).			
	Accepting gratitude	CG acknowledges gratitude expressed by the resident. Could be a 'you're welcome' or other simple verbal form of acknowledgement. 1 clip	R: “What do, what, where does this belong? … Thank you.” CG: “Hmmm mmm.” 514-3-39a
	Affirming dissenting response	Similar to 'agreeing with resident', but different and specific in that the CG affirms the resident's refusal, allowing the resident to refuse, which may begin a process of negotiation. 1 clip	CG: “Are you ready, *resident’s name*?” R: “No.” CG: “No?” R: “No.” CG: “Ok, well, let’s give it a couple more minutes, then we’ll bring our legs out and get

			in your chair, ok?" 543-2-38
	Agreeing with or answering illogical statement	Statement by resident is either unintelligible or illogical, but CG agrees or attempts to answer the illogical question. 9 clips	R: "Who's there?" CG: "Hmmm?" R: "Who's there?" CG: "Where?" R: "Here." CG: "Here?" R: "Yeah." CG: "This is your clothing." 514-2-9
	Agreeing with resident	In response to a resident's verbalization, CG expresses agreement with the resident. May also be interpreted as an expression of understanding, and having heard the resident. May be expressed by saying, 'ok' before further responding to the resident. 21 clips	R: "Is it hot?" CG: "Let's see." R: "It's hot." CG: "Yeah, it is. Let's make it a little cooler. Ok. I think that's better." R: "I think so." 514-3-33
	Answering resident's question logically	CG answers the resident's question in the most logical way possible, based on the CG's interpretation of the question's intent. 5 clips	R: "Why are you gonna, why are you taking these off?" CG: "So that we can put these ones on, ok?" R: "Oh, I see." 514-3-6
	Asking about a speculation	In response to resident's verbalization, the CG asks if the reason for the resident's concern is due to what the CG suspects. 1 clip	R: "My eyes are, are practically half closed." CG: "Are they? Hmmm." R: "Yes." CG: "You still sleepy?" 514-3-44

	Asking resident to repeat self	In response to resident’s verbalization, the CG asks the resident to repeat what he/she said. 1 clip	R: “Who’s there?” CG: “Hmmm?” R: “Who’s there?” 514-2-9
	Checking an interpretation	In response to a resident's verbalization, CG asks resident if he/she interpreted correctly. For example, to a stuttering vocalization, the CG says, “hurry up and get it over with, right?” 2 clips	CG: “I’m sorry, you have to put a clean one on.” R: (stuttering vocalizations) CG: “Come on an hurry up, right?” 534-5-17
	Clarifying	In response to a resident's verbalization, CG asks a clarifying question or responds with an inquiry into the comment, such as "oh, are they?" that appears to help gather more information or verify information for the CG. 7 clips	R: “It’s a little bit too long now.” CG: “Where, down here?” R: “Hmm mmm.” 514-3-22
	Conveying understanding	In response to resident’s verbalization, CG responds to let the resident know s/he heard and understood the resident. The response may be as simple as ‘ok’, or have a more empathetic tone, like, ‘I know’. The later response occurred when the resident was expressing a negative experience. 8 clips	CG: “…ok, let’s do this side… R: “Oh, g-dammit.” CG: “I know, we’re almost done.” 514-4-9
	Distracting	CG response moves resident's attention away from present focus or activity. The CG seems to be attempting to help the resident 'move	R: “What do they do on that?” CG: “Well, come over here, let me show you something here. Turn right here.”

		on'. 4 clips	R: (unintelligible phrases) 514-2-3
	Expressing amusement or humor	CG may laugh in response to resident's comment, or may laugh in response to increasing tension or frustration. 13 clips	R: "Isn't that funny, boy, they just, they really, really love it, huh?" CG: (laughing) 514-2-2
	Expressing different perspective	In response to resident's comment, CG offers his/her alternative perspective. Could be viewed as disagreeing with the resident or attempting to move the resident past a 'sticking point'. 2 clips	R: "It's a little bit too long now." CG: "Where, down here?" R: "Hmm mmm." CG: "Well, I think it's just fine." R: "That's too long. That's not good. No." CG: "No?" R: "No." CG: "Here, let's pull it up a little bit more." 514-3-22 & 23
	Expressing thanks	In response to resident's verbalization or assistance, CG expresses a thank you. Often in response to a compliment from the resident. 1 clip	CG: "Can you hold that right there for me?" R: "Yes, I can." CG: "Thank you." R: "Yes" 514-2-21
	Expressing wondering	In response to a resident's verbalization, CG expresses wondering or uncertainty, such as "hmmm..."	R: "My eyes are, are practically half closed." CG: "Are they? Hmmm." R: "Yes." CG: "You still sleepy?"

			514-3-44
	Interpreting - Explaining	CG interprets vocalizations or illogical verbalizations from resident and in response, offers further explanation for the current or upcoming activity. 2 clips	CG: “This one is dirty.” R: (stuttering vocalizations) CG: “You slept in this one last night, *resident’s name*.” 534-5-14
	Interpreting-instructing/informing	CG interprets the content of the verbalization or vocalization and chooses to respond with instruction or information. 4 clips	CG: “Let’s take them off.” R: (stuttering vocalizations) CG: “Ok, let’s take them off. R: (stuttering vocalizations) CG: “Come on honey, let’s take it off. We’ve got a nicer one for you. This one is dirty.” 534-5-15
	Interpreting-reassuring	CG responds to a vocalization or illogical verbalization by reassuring the resident. Because vocalizations are unclear, the CG must be making an interpretation of the meaning of the vocalization. If this code is used, the CG has not 'checked the interpretation', but instead acts on their assumed interpretation. 2 clips	R: (stuttering vocalizations) CG: “It’s ok, you’ll be ok. Let’s put your pants on.” 534-5-4
	Interrupting	While the resident is speaking or vocalizing in some way, the CG talks over the resident.	R: “Makes you feel…” CG: “Let’s make sure your pants are straight.” R: “Yeah, it better,” CG: “OK.” R: “I hope.” 514-2-23
	No response	Resident makes some	R: “What’s this doing here?”

		verbalization/vocalization and CG does not respond to this directly in any way. 20 clips	CG: “Oh, those are towels. So, we’re going to use them right now.” R: “We are?” R: “Hmmm?” 514-3-28
	Repeating statement for resident	Usually in response to a resident who expresses that he/she has not heard CG correctly, CG repeats or restates the previous statement.	CG: “Get your belly –“ R: “Huh?” CG: “Get your belly clean.” 514-4-7
	Repeating the resident's response	In response to a resident's verbalization, CG repeats what the resident says.	CG: “Are you going to be ready to sit up on the edge of the bed so we can get your shirts on? Huh?” R: “Uh huh.” C: “Uh huh?” 514-4-20
	Responding to a different question or statement	A question or statement has been made by the resident, but the CG responds to some kind of different question or statement, related or not. 4 clips	R: “Wonder where that goes?” CG: “Here, I’ll hold it.” 514-2-16
	Stating CG response	In response to the resident’s verbalization/vocalization, the CG states what he/she will do to respond to the resident expressed need, concern, or question. 14 clips	R: “Oh boy, oh, it’s cold.” CG: “I know, I’m going to grab you a dry blanket to put on.” R: “Oh my, it’s so cold.” 514-4-21

Appendix C. Initial classification of raw verbal interaction codes

CATEGORY DEFINITION	CODE	CODE DEFINTION	CLASSIFICATION
Apologizing Within the verbal content, the CG acknowledges some fault or offense, with an expression of remorse for it.			
	Acknowledging mistake	CG expresses awareness of having made a mistake that affected the resident negatively. (2 clips with this code)	Positive, potentially person-centered
Asking Questions A description of any verbal content from a CG that is in the form of a question to the resident.			
	Asking about basic needs	Caregiver asks resident if he/she is hungry, thirsty, tired, cold, or needing to toilet. (3 clips with this code)	Positive, associated with good care
	Asking about likes/dislikes	Asking resident, in a yes/no manner, about their like or dislike of an object or whether they would like an article of clothing. (5 clips with this code)	Positive, potentially person-centered
	Asking about pain	Either as a course of interaction or in response to some indication by the participant, CG asks resident about the specific issue of pain or otherwise expresses concern that the resident is physically ‘ok’.	Positive, potentially person-centered

		(4 clips)	
	Asking about well-being	CG asks, often in a polite and conventional manner, ‘how are you today?’ or ‘did you sleep well?’ (1 clip)	Positive, associated with good care
	Asking again for a response	A follow up from an initial question that the resident hasn't answered. May be as simple as ‘hmmm?’ or ‘huh?’ or it may involve repeating a portion of the question, or repeating the question in its entirety. (13 clips)	Positive, potentially person-centered
	Asking for confirmation about CG’s perception	Asks a question in which the CG’s perception about the situation is offered. The resident need only to confirm the perception, and there seems to be an assumption that the resident will say ‘yes’. (7 clips)	Positive, potentially person-centered
	Asking for feedback about care	CG specifically asks resident for input about the process of care delivery. Often takes the form of "how was that?" or "ok?" or ‘How’s that feel?” (8 clips)	Positive, potentially person-centered
	Asking if resident has completed task	Asking if the resident is done with an independent activity (e.g. urinating, washing hands). (3 clips)	Positive, associated with good care
	Asking if resident is able	By way of a question of ability (i.e., Can	Positive, associated with good care

	and willing to perform an action	you bend your knee?) CG prompts resident to assist/facilitate the care process by doing something or moving to a different position. (6 clips)	
	Asking resident for assistance with an activity	CG asks resident to help in some way with the completion of the activity, (e.g., positioning clothing, holding undergarment in place). (2 clips)	Positive, associated with good care
	Suggesting a choice in participation	By way of a yes/no question, the CG asks the resident for permission, either directly or indirectly, or asks about readiness to move forward with the next activity. Or, CG may place an ‘ok?’ at the end of information or instruction about the caregiving process/activity. (12 clips)	Positive, potentially person-centered
Commenting A description of the verbal content of the CG that constitutes a comment and is not better described by another category. A comment is generally uni-directional; there is no expectation of a response from the resident.			
	Acknowledging cooperation	Brief comment from CG that makes note of the resident's cooperation. (1 clip)	Positive, associated with good care
	Commenting	CG says something	Negative

	about a negative habit	about a negative habit of the resident. Uni-directional; CG doesn't appear to be expecting a response. (2 clips)	
	Commenting about an object	CG makes a comment about an object (e.g. an article of clothing) that is unrelated to the utility of the object or information about the object (2 clips)	Positive, associated with good care
	Commenting about how positive the activity should feel to the resident	CG expresses either an intent or hope that the resident is experiencing the activity in a positive way. (1 clip)	Positive, associated with good care
	Commenting about involuntary actions	CG uses an event such as a yawn by the resident as a topic for a comment, may be unidirectional or could be interpreted to be initiating conversation (1 clip)	Positive, associated with good care
	Expressing regret	CG expresses regret in some manner. May be a quick or passing, 'I'm sorry', that conveys awareness that the resident has little choice in the activities underway, or that the process of care is at times uncomfortable. (2 clips)	Positive, associated with good care
	Marking general progress	CG uses very general terms to comment that some progress has been made in the activity at hand, (e.g. ‘there’, or ‘ok’) 20	Neutral

		clips	
	Rhetorical question	A comment in the form of a question, the CG asks a question, but there's no evidence of desire for or expectation of a response. (2 clips)	Neutral
Complimenting A description of the verbal content of the CG that takes the form of praise or flattery.			
	Complimenting	A positive comment made to the resident about the resident's physical appearance. (3 clips)	Positive, associated with good care
Encouraging A description of the verbal content of the CG that takes the form of supportive words that impart confidence or inspiration to the resident.			
	Approving words	CG offers supportive words to resident, usually about activity that is occurring or has just occurred, or as a statement of belief in the resident's ability or capacity to complete a task. (10 clips)	Positive, associated with good care
	Supporting independent activity	CG encourages resident in independently doing the activity by conveying that the CG won’t be doing the activity for the resident. For example,	Positive, potentially person-centered

		the CG may say to the resident, I'll let you do that (put on your shirt)', implying that he/she won't be doing that. (3 clips)	
Explaining The verbal content of the CG seeks to provide a reason the resident is being expected to do the activity at hand.			
	Explaining why	Offering a rationale for the current activity or upcoming action. (22 clips)	Positive, associated with good care
Extra Terms			
	Terms of endearment	CG uses an endearing term when referring to the resident, such as 'honey' or 'sweetie'. 15 clips	Neutral - debated
	Polite terms	Within the verbal content, CG uses polite terms such as 'please' or 'thank you'. 3 clips	Positive, associated with good care
	Using resident's name	Within the verbal content, the caregiver uses the resident's name. 38 clips	Positive, associated with good care
Getting Resident's Attention The verbal content of the CG's speech is used to increase the likelihood that the resident is listening to the CG.			
	Getting resident's attention	Through some verbal means, CG seeks to get resident's attention, often by saying their	Neutral

		name before speaking, or saying, "here,..." to hold their attention before providing new information. 14 clips	
	Using an engaging question	Through the use of an engaging question such as, 'you know what?', the CG appears to attempt to shift the topic or focus of activity toward some other task. May be used as a means of distracting a resident who is perseverating. 1 clip	Positive, associated with good care
Greeting The verbal content of the caregiver's speech is a traditional greeting to the resident.			
	Good morning	Caregiver greets resident with a formal 'good morning' of some sort. 1 clip	Positive, associated with good care
Informing The verbal content of the CG's speech is used to provide information necessary for the task at hand.			
	Informing about an object	Identification of or description of characteristics of an object that facilitates its use. 7 clips	Positive, associated with good care
	Informing about the process or activity	Usually uni-directional, CG tells resident some information about the 'what' of present or future activities. Or, CG may tell the resident that he's	Positive, associated with good care

		leaving the room for some purpose. 87 clips	
	Informing the resident about him/herself or action	CG makes an observational/informing statement that simply describes something related to the resident, either a like/dislike, or something about their position, actions, or physical appearance. 4 clips	Positive, associated with good care
	Informing about timing	CG tells resident about the timing or sequencing of an activity or action. May be announcing immediate or impending activity. 28 clips	Positive, associated with good care
	Informing about what the CG needs from the resident	Stated in an 'I need you to...' phrase, the CG states a need and at the same time informs the resident of what's getting ready to happen. Typically that the CG needs the resident to move in some way in order to finish the task. 3 clips	Positive, associated with good care
	Suggesting an activity	Caregiver uses a sentence structure that is suggestive rather than directive, such as, “let’s do this one” or “let’s go to the dining room”. 11 clips	Positive, potentially person-centered (variation on ‘asking permission’)
Instructing The verbal content of the CG’s speech is used to provide instructions necessary for completing the task at hand.			

	Giving instructions	Instructing or directing resident during care activity in a manner to assist the resident in completing the activity. 64 clips	Positive, associated with good care
	Instructing resident to let CG help	CG makes self available for helping resident. Sentence structure may be "let me help you" or "turn this way, I can help you with that"... 2 clips	Neutral, situation specific
	Presenting an object	CG presents an object or article of clothing, identifies it and hands it to the resident, expecting resident to take it as it is needed for the next activity or for finishing care. 4 clips	Neutral
	Repeating instruction	Restating the instructions to the resident to reinforce the instruction, restate them in a way that improves understanding, or in response to a question by the resident. 19 clips	Uncertain
Language Usage/Phrasing Description of 'how' (not what) information is communicated to the resident.			
	Speaking from the CG perspective	While instructing, speaks from CG point of view, such as, "turn my way" or "I want you to wear this". 6 clips	Neutral, could be argued to be negative

	Using plural pronouns	CG says 'let's', 'we', or 'our' when instructing or giving information to the resident. For example, “We’re going to swing our legs to the edge of the bed.” 64 clips	Uncertain
	Using formal or technical terms	Describes or names objects using a technical/medical or formal term that the person with dementia may not be familiar with, such as 'Attends' or 'peri-area'. 6 clips	Neutral, could be argued to be negative
	Abstract phrases	Caregiver uses fairly abstract phrases that may be difficult for the person with dementia to interpret. For example, “I'm going to get the sleep out of your eyes." 10 clips	Neutral
Negotiating The verbal content of the speech of the CG communicates the desire to overcome an obstacle by reaching a mutual agreement by way of compromise.			
	Suggesting an alternative	In response to dissent from the resident, the CG offers an alternative plan in order to complete the activity at hand. 4 clips	Positive, potentially person-centered
Reassuring The verbal content of the speech of the CG restores a sense of			

confidence for the resident.			
	Reassuring	CG offers positive words to affirm resident's safety or to instill confidence, usually after the resident has expressed misgivings, distinguishing it from ‘encouraging’. Reassuring, in this sense, is expressed in a fairly concrete way, such as 'it's ok' or 'that’s fine’. 2 clips	Positive, associated with good care
Responding to Actions A description of the verbal content of a CG that is specifically in response to an action or behavior by the resident.			
	Affirming resident’s action	CG uses approving words in response to the resident doing some independent activity. In some cases the CG may seem to be 'granting permission' for the activity, as if he/she isn't going to do anything to stop the resident, but the verbal response and phrasing conveys that the CG is in control. 2 clips	Positive, potentially person-centered
	Checking an interpretation	In response to the resident's actions, the CG seeks to confirm his/her interpretation of the action. 4 clips	Positive, potentially person-centered
	Giving additional	In response to the resident's actions, CG	Positive, associated with good care

	instruction	offers additional instruction. This will also be captured under the category heading: ‘Instructing' 8 clips	
	Instructing resident to let CG help	In response to resident's actions/behaviors, CG offers help. This may be appropriate, if the resident is having difficulty, or inappropriate, if the resident is independent but the CG desires to assist for expediency. 1 clip	Neutral
	Interpreting assent to proposed activity	Based on activity, lack of activity, or posture, CG interprets resident's behavior as assenting to the proposed task. 1 clip	Uncertain
	Interpreting dissent or completion of activity	CG interprets behavior of resident as communicating that the resident is declining the proposed activity or is 'done' with the activity underway. 5 clips	Uncertain
	No response	When an independent action, separate from completing a caregiving task is initiated by the resident, the CG offers no verbal response. 3 clips	Negative
	Stating CG response	In response to the resident’s actions/behaviors, CG tells the resident what he/she will do. 5 clips	Positive, associated with good care
Responding to			

Verbalizations or Vocalizations A description of the verbal content of the CG's speech specifically in response to the resident's verbalization or vocalization (non-intelligible vocal utterance).			
	Accepting gratitude	CG acknowledges gratitude expressed by the resident. Could be a 'you're welcome' or other simple verbal form of acknowledgement. 1 clip	Positive, associated with good care
	Affirming dissenting response	Similar to 'agreeing with resident', but different and specific in that the CG affirms the resident's refusal, allowing the resident to refuse, which may begin a process of negotiation. 1 clip	Positive, potentially person-centered
	Agreeing with or answering illogical statement	Statement by resident is either unintelligible or illogical, but CG agrees or attempts to answer the illogical question. 9 clips	Positive, associated with good care
	Agreeing with resident	In response to a resident's verbalization, CG expresses agreement with the resident. May also be interpreted as an expression of understanding, and having heard the	Positive, uncertain

		resident. May be expressed by saying, 'ok' before further responding to the resident. 21 clips	
	Answering resident's question logically	CG answers the resident’s question in the most logical way possible, based on the CG's interpretation of the question's intent. 5 clips	Positive, associated with good care
	Asking about a speculation	In response to resident's verbalization, the CG asks if the reason for the resident's concern is due to what the CG suspects. 1 clip	Positive, potentially person-centered
	Asking resident to repeat self	In response to resident’s verbalization, the CG asks the resident to repeat what he/she said. 1 clip	Positive, potentially person-centered
	Checking an interpretation	In response to a resident's verbalization, CG asks resident if he/she interpreted correctly. For example, to a stuttering vocalization, the CG says, “hurry up and get it over with, right?” 2 clips	Positive, potentially person-centered
	Clarifying	In response to a resident's verbalization, CG asks a clarifying question or responds with an inquiry into the comment, such as "oh, are they?" that appears to help gather more information or verify information for the	Positive, potentially person-centered

		CG. 7 clips	
	Conveying understanding	In response to resident’s verbalization, CG responds to let the resident know s/he heard and understood the resident. The response may be as simple as ‘ok’, or have a more empathetic tone, like, ‘I know’. The later response occurred when the resident was expressing a negative experience. 8 clips	Positive, associated with good care
	Distracting	CG response moves resident's attention away from present focus or activity. The CG seems to be attempting to help the resident 'move on'. 4 clips	Positive, associated with good care
	Expressing amusement or humor	CG may laugh in response to resident's comment, or may laugh in response to increasing tension or frustration. 13 clips	Positive, associated with good care
	Expressing different perspective	In response to resident's comment, CG offers his/her alternative perspective. Could be viewed as disagreeing with the resident or attempting to move the resident past a 'sticking point'. 2 clips	Positive, potentially person-centered
	Expressing thanks	In response to resident's verbalization or assistance, CG expresses a thank you. Often in response to a	Positive, associated with good care

		compliment from the resident. 1 clip	
	Expressing wondering	In response to a resident's verbalization, CG expresses wondering or uncertainty, such as "hmmm..."	Neutral
	Interpreting - Explaining	CG interprets vocalizations or illogical verbalizations from resident and in response, offers further explanation for the current or upcoming activity. 2 clips	Uncertain
	Interpreting-instructing/informing	CG interprets the content of the verbalization or vocalization and chooses to respond with instruction or information. 4 clips	Uncertain
	Interpreting-reassuring	CG responds to a vocalization or illogical verbalization by reassuring the resident. Because vocalizations are unclear, the CG must be making an interpretation of the meaning of the vocalization. If this code is used, the CG has not 'checked the interpretation', but instead acts on their assumed interpretation. 2 clips	Neutral, situation specific
	Interrupting	While the resident is speaking or vocalizing in some way, the CG talks over the resident.	Negative
	No response	Resident makes some	Negative

		verbalization/vocalization and CG does not respond to this directly in any way. 20 clips	
	Repeating statement for resident	Usually in response to a resident who expresses that he/she has not heard CG correctly, CG repeats or restates the previous statement.	Positive, associated with good care
	Repeating the resident's response	In response to a resident's verbalization, CG repeats what the resident says.	Neutral
	Responding to a different question or statement	A question or statement has been made by the resident, but the CG responds to some kind of different question or statement, related or not. 4 clips	Negative
	Stating CG response	In response to the resident's verbalization/vocalization, the CG states what he/she will do to respond to the resident expressed need, concern, or question. 14 clips	Positive, associated with good care

Appendix D. Analysis of codes classified as *potentially person-centered* or *uncertain* with rationale and resulting determination

RAW CODE	CODE DEFINTION	CLASS-IFICATION	RATIONALE	DETERMINATION
Asking about likes/dislikes	Asking resident, in a yes/no manner, about their like or dislike of an object or whether they would like an article of clothing.	Positive, potentially person-centered Considered *toward* person-centered care, but lacked completeness as it was observed in the data.	Based on the theoretical definition of <u>knowing the person</u>: avoiding assumptions, centering on the one being cared for, and emphasizing the individual preferences of the resident, the meaning of *asking about likes/dislikes* appears person-centered. The attempt in the interaction appears to be moving toward the critical attribute of <u>knowing the person</u>. Additionally, underlying the question is a degree of choice. The question is presumably asked in order to provide an option, soliciting information about likes/dislikes in order to accommodate to the stated preference. Any time questions such as these are asked, the person cared for is valued (personhood) and less objectified. The relationship is strengthened as interest is shown in the preferences of the person receiving care.	Included, but revised to *asking about preferences.*
Asking about pain	Either as a course of interaction or in response to some indication by the participant, the caregiver asks resident about the specific issue of pain or otherwise expresses	Positive, potentially person-centered	Similar to *asking about likes/dislikes,* the descriptive code *asking about pain* integrates the critical attributes of person-centered care. When a caregiver asks about pain, they are inherently avoiding assumptions, they are centering on the one being cared for and they are	Included with revisions. Asking about comfort as well as pain is viewed as essential to the provision of person-centered care that

	concern that the resident is physically ‘ok’.		promoting the value and dignity of the person. The relationship (trust) is strengthened as interest is shown in the comfort and pain needs of the person receiving care. Finally, asking questions suggests an apparent desire to address whatever pain/comfort needs arise, fostering the supportive environment and choice associated with person-centered care.	focuses on the unique and immediate needs of the person. *Asking about pain and comfort* is the revised term.
Asking again for a response	A follow up from an initial question that the resident hasn't answered. May be as simple as ‘hmmm?’ or ‘huh?’ or it may involve repeating a portion of the question, or repeating the question in its entirety.	Positive, potentially person-centered Considered *toward* person-centered care, but lacked completeness as it was observed in the data.	*Asking again* suggests sincerity and intentionality in the act of asking and genuine interest in the person’s response. In so doing, it conveys that the person is valued, minimizes objectifying activities and conveys a genuine desire for relationship. It keeps the door wide open, even pulling the person through to a response that allows the caregiver to then address the response. When paired with a question about preferences, it further encourages choice, conveys a desire to avoid assumptions, and sends a message of shared control.	Included with revision to the label. *Trying again for input* is the revised term.
Asking for feedback about care	The caregiver specifically asks resident for input about the process of care delivery. Often takes the form of "how was that?" or "ok?" or ‘How’s that feel?”	Positive, potentially person-centered Considered *toward* person-	This kind of ‘checking in’ conveys a desire to accommodate the resident’s needs and preferences, a desire to avoid the assumption that everything is going well, an active seeking of cues, a willingness to alter the approach and suggests a willingness to share the	Included, shortened to *asking for feedback*.

		centered care, but lacked completeness as it was observed in the data.	control over the process. When questions such as this are asked, the person cared for is valued, less objectified and their immediate experience of the caregiving event is solicited. The relationship is strengthened as the caregiver expresses interest in the resident's experience of care.	
Suggesting a choice in participation	By way of a yes/no question, the caregiver asks the resident for permission, either directly or indirectly, or asks about readiness to move forward with the next activity. Or, caregiver may place an 'ok?' at the end of information or instruction about the caregiving process/activity.	Positive, potentially person-centered Considered *toward* person-centered care, but lacked completeness as it was observed in the data.	In the data, the nonverbal context of this code was perfunctory and indirect; the words did not match the tone of voice. The caregivers typically said, "ok?" at the end of providing information about the next care task, and did not always wait for a response. The question arose as to whether there was really a choice being offered, thus the language of 'suggesting' was used in the raw coding. Truly offering a choice and asking permission conveys shared control and power, seeks information about the individual needs and readiness of the other, suggests a willingness to accommodate to the wishes of the resident, and minimizes objectifying interactions. In an extension from the data, the idea of *asking permission* integrates the critical attributes of person-centered care into the caregiving act.	Included with revisions. This observational code was revised to *asking permission.*
Suggesting an alternative	In response to dissent from the resident, the	Positive, potentially	Standing alone, the raw code and its meaning do not represent a uniquely	Included with revised label: *Offering 'Plan*

plan for care receiver who is reluctant or resistant	caregiver offers an alternative plan in order to complete the activity at hand.	person-centered	person-centered interaction. However, suggesting an alternative is identified as a strategy within a process of negotiating resistance that is person-centered. By suggesting an alternative, the caregiver refrains from trying to push through the resistance and instead seeks to find a place of agreement. This aspect of negotiation is congruent with an integration of the critical attributes of person centered care: maintaining relationship (by managing conflict and fostering trust), maximizing control and freedom of choice, and engaging the self of both.	*B'* as a strategy within a person-centered negotiation process.
Checking an interpretation	In response to the resident's actions, the caregiver seeks to confirm his/her interpretation of the action, or In response to a resident's verbalization, the caregiver asks resident if he/she interpreted correctly. For example, to a stuttering vocalization, the caregiver says, "hurry up and get it over with, right?"	Positive, potentially person-centered	Uniquely person-centered and supported in the data. *Checking an interpretation* congruent with the guiding definition and proposed attributes in that this particular interaction avoids assumptions, seeks the meaning of cues and by doing so is centered on the person receiving care. By expressing the desire to gain clarity about the person's cue, the caregiver fosters trust in the relationship and implies a desire to follow guidance from the person in order to alter care as needed. This simple act communicates value to the person, and provides a supportive environment for care.	Included with alteration to the label to better express the definition and for improved understanding. *Checking the meaning of cues* was included.
Affirming	Similar to 'agreeing with	Positive,	The act of affirming the person's	Included, but with

dissenting response	resident', but different and specific in that the caregiver affirms the resident's refusal, allowing the resident to refuse, which may begin a process of negotiation.	potentially person-centered	dissenting action conveys an acceptance of personhood as distinct and unique from the caregiver, with differing preferences and desires. It also suggests shared control; the person receiving care is leading the process, making a choice for herself and the caregiver is affirming this as positive. As affirmation is provided, the relationship is strengthened and the person valued. This code also represents an initial response to any form of resistance that then begins a negotiation process before care tasks move forward. By accepting and not escalating the resistance, the caregiver alters her plan for completing tasks to accommodate the person’s actions.	revisions to the label. *Accepting resistance* is the chosen label.
Clarifying	In response to a resident's verbalization, caregiver asks a clarifying question or responds with an inquiry into the comment, such as "oh, are they?" that appears to help gather more information or verify information for the caregiver.	Positive, potentially person-centered	The raw code *clarifying* and its associated description is inherently congruent with the guiding definition in that by clarifying, the caregiver is avoiding assumptions or acting on misinterpretations, the caregiver is actively seeking information and response from the person and is thus centered on the person. By clarifying responses, the caregiver conveys a desire to know the person which communicates value which then fosters relationship. When a caregiver clarifies responses to questions about the care experience, the	Included with a revision to the label. *Clarifying responses* is the revised label.

			caregiver indirectly offers choice and fosters control. Only when the caregiver understands the preferences of the person can he/she accommodate them, making clarifying a critical aspect of person-centered caregiving interaction.	
Expressing different perspective	In response to resident's comment, the caregiver offers his/her alternative perspective. Could be viewed as disagreeing with the resident or attempting to move the resident past a 'sticking point'.	Positive, potentially person-centered	At face value the term *Expressing a different perspective* is not uniquely person-centered, but it was identified as a strategy within a person-centered negotiating process and thus is included as it helps to operationalize of *Negotiating resistance*. It is heavily dependent on skilled nonverbal interactions to avoid appearing argumentative or dismissive. With the use of sophisticated nonverbal skills, the caregiver disagrees with the person receiving care while supporting the goal of reaching a mutually agreeable solution.	Included, with slight alteration to the original language. *Offering a different perspective* was determined to best capture the intent of this strategy within *Negotiating resistance.*
Following the lead of the person receiving care.	In response to an active cue from the person receiving care, the caregiver changes his/her immediate actions in order to verbally or physically assist the person receiving care.	Positive, potentially person-centered	As observed in the data, this code and definition correspond to the assumptions and definitions guiding the study. Following the lead of the person receiving care promotes freedom of action and maximizes control for the person with dementia.	Included with slight revision to the label for simplicity. *Following their lead* is the phrase used to reflect this aspect of person-centered caregiving interaction.
Increasing	In response to an active or	Positive,	Increasing assistance, as observed in the	Included

assistance	verbal cue from the person receiving care, the caregiver makes an adjustment to the way care was being delivered and increases the amount of hands-on assistance or offers more specific verbal cues so that the care receiver can complete the activity.	potentially person-centered	data in response to a behavioral cue, is argued to be person centered in that it alters care to accommodate the needs of the resident. Any act of accommodation communicates value and maintains the uniqueness of the individual. It inherently suggests that the person receiving care is guiding the process when needs and preferences are noted and accommodated.	
Stopping care activity	In response to some behavioral or verbal/vocal cue from the person receiving care, the caregiver stops their activity. The time-frame for stopping care may vary. A simple pause may be sufficient in some cases; other circumstances may lead the caregiver to stop the activity in order to enter into negotiating care, or even to end the caregiving altogether in order to come back another time.	Positive, potentially person-centered	Within the context of responding to some verbal or behavioral cue from the person receiving care, stopping the activity is viewed person-centered as it promotes choice by opening the way for negotiation; it alters the immediate caregiving environment to accommodate needs and preferences, and creates an opportunity to maximize control for the person receiving care.	Included
Stating caregiver's response	In response to verbal expressions of need or preference, or action	Positive, potentially person-	In the context of a completed interaction cycle (not just stating what the caregiver will do, but following through on the	Included in revised form. *Following through* is a phrase

	behaviors with a clear intent, the caregiver acknowledges the information and informs the person receiving care how he/she will address the information. 'Following through' also includes some action that indicates the caregiver is acting on the information received.	centered	information) to expressed needs, requests, stated preferences, or other cues from the person receiving care, following through on a request is considered uniquely person-centered. This act supports the guiding definitions and attributes of accommodating, and maximizing control. In addition, it honors the person's uniqueness as an individual.	that better reflects the intent of the original code.
Repeating an action to improve care receiver response	In response to a behavioral or verbal/vocal cue of dissatisfaction or discomfort during a specific caregiving task, the caregiver performs the same task differently, repeating with slight adjustments to the action until the cues or feedback indicate satisfaction.	Positive, potentially person-centered	This code reflects the active process of altering the immediate caregiving situation to accommodate preferences of the person receiving care. This act of accommodating is one of the core attributes underlying person centered care. Any act of accommodation communicates value and maintains the uniqueness of the individual.	Included in revised form. *Trying again to get it right* is the phrase selected to simply describe this caregiver interaction.
Going along	At the end of the process of negotiating, the caregiver defers to the person receiving care, either asking for permission to move forward with the negotiated new plan or	Positive, potentially person-centered	*Going along* was identified as a strategy within a person-centered negotiating process and thus is included as it helps to operationalize of *Negotiating resistance*. Independently, it is not representative of integrated critical attributes, but rather is a step in the observed negotiation process for managing resistance in a person-	Included

	simply beginning to act on the plan indicated by the person receiving care.		centered way. It is descriptive of the act of moving forward after negotiation is believed to be complete.	
Affirming resident’s action	The caregiver uses approving words in response to the resident doing some independent activity. In some cases the caregiver may seem to be 'granting permission' for the activity, as if he/she isn't going to do anything to stop the resident, but the verbal response and phrasing conveys that the caregiver is in control.	Positive, potentially person-centered	With further analysis, this raw code appeared to overlap conceptually with two other raw codes, *agreeing with resident*, and *affirming a dissenting response*. Ultimately the description of this code was folded in to the person-centered negotiation strategy, *going along*.	Not included
Agreeing with resident	In response to a resident's verbalization, the caregiver expresses agreement with the resident. May also be interpreted as an expression of understanding, and having heard the resident. May be expressed by saying, 'ok' before further responding to the resident.	Positive, uncertain	Upon further examination, *agreeing with resident* appeared conceptually blurred with *affirming dissenting response* and *affirming resident’s action.* Agreeing with the resident may or may not be person-centered, making the general code label less useful. Reflection on what aspects or instances of *agreeing with the resident* are person-centered led to a decision that agreement associated with the more precise codes *going along* and *accepting resistance* was the aspect that was uniquely person-centered. Other general instances of agreeing are associated with good dementia care.	Not included

Asking about a speculation	In response to resident's verbalization, the caregiver asks if the reason for the resident's concern is due to what the caregiver suspects.	Positive, potentially person-centered	Ultimately viewed as overlapping with the code *checking an interpretation* and with the broader category of *Clarifying Ambiguity* and not included.	Not included
Asking resident to repeat self	In response to resident's verbalization, the caregiver asks the resident to repeat what he/she said.	Positive, potentially person-centered	Ultimately viewed as overlapping with *clarifying responses* and was not included.	Not included
Acknowledging mistake	Caregiver expresses awareness of having made a mistake that affected the resident negatively.	Positive, potentially person-centered	With further consideration, *acknowledging mistake* is an expected aspect of good care, but does not represent all attributes of person-centered care. *Acknowledging mistake* incorporates value and honors personhood, and demonstrates an empathic manner of relating. However, there is nothing inherent in the meaning of the code that represents the characteristics of <u>Knowing the person</u> (e.g., striving to understand the meaning of events for the resident, seeking cues) or facilitating choice and control. The term is more passive, reflecting compassionate and humane aspects of caring, but this way of caring is not fully descriptive of person-centered interactions.	Not included
Asking for confirmation	Asks a question in which	Positive,	Ultimately viewed as overlapping with	Not included

about the caregiver’s perception	the caregiver’s perception about the situation is offered. The resident need only to confirm the perception, and there seems to be an assumption that the resident will say ‘yes’.	potentially person-centered	the code *checking an interpretation* and with the broader category of *Clarifying Ambiguity* and not included.	
Interpreting assent to proposed activity	Based on activity, lack of activity, or posture, caregiver interprets resident's behavior as assenting to the proposed task.	Uncertain	Upon further reflection and analysis, the raw codes based on a clear interpretation by the caregiver were not included. This decision was made as these interpretation codes were superseded by the code *Checking an interpretation.* This latter code was held to be person-centered in contrast to these *interpreting assent* or *interpreting dissent* because by checking out the caregiver’s interpretation of an action, response or cue, the caregiver avoids misinterpretation and thus avoids acting on an assumption or misinterpretation of an action, response, or cue. The act of checking the interpretation with the resident is central to avoiding assumptions and placing the person receiving care in the position to guide care whenever possible.	Not included
Interpreting dissent or completion	Caregiver interprets behavior of resident as communicating that the	Uncertain	See rationale for above, *Interpreting assent to proposed activity*	Not included

of activity	resident is declining the proposed activity or is 'done' with the activity underway.			
Interpreting - Explaining	The caregiver interprets vocalizations or illogical verbalizations from resident and in response, offers further explanation for the current or upcoming activity.	Uncertain	See rationale for above, *Interpreting assent to proposed activity*	Not included
Interpreting-instructing/informing	The caregiver interprets the content of the verbalization or vocalization and chooses to respond with instruction or information.	Uncertain	See rationale for above, *Interpreting assent to proposed activity*	Not included
Supporting independent activity	Caregiver encourages resident in independently doing the activity by conveying that the caregiver won't be doing the activity for the resident.	Positive, potentially person-centered	With further reflection, this code is determined to be limited to good dementia care. *Supporting independent activity* conveys confidence in the person's remaining abilities and strengths. It also requires that the caregiver always be always assessing the person's abilities, which may be different at different times. Fundamentally, value for the person is conveyed and dignity is potentially preserved, making *supporting independent activity* an important aspect of good dementia care, but because it inherently lacks the attributes of	Not included.

			soliciting and accommodating to the resident's preferences and choices it is not believed to be person-centered.	
Suggesting an activity	Caregiver uses a sentence structure that is suggestive rather than directive, such as, "let's do this one" or "let's go to the dining room".	Positive, potentially person-centered (variation on 'asking permission')	With additional analysis, this code was subsumed under *asking permission*.	Not included
Repeating instruction	Restating the instructions to the resident to reinforce the instruction, restate them in a way that improves understanding, or in response to a question by the resident.	Uncertain	Upon additional reflection and analysis, *repeating instruction* is believed to be an aspect of good dementia care. It is expected in all caregiving arenas; not to repeat an instruction would be neglectful. Simply repeating an instruction does not exemplify the core attributes of person-centered care, it does not further the caregiver's knowledge of the person, it does not aid in seeking cues, it does not foster choice or relationship.	Not included
Using plural pronouns	Caregiver says 'let's', 'we', or 'our' when instructing or giving information to the resident. For example, "We're going to swing our legs to the edge of the bed."	Uncertain	Using plural pronouns to refer to only one person may or may not communicate a message of mutuality to the person receiving care. This style of communication does not independently support choice or control, not does the use assist the caregiver in better knowing the person. It is not included as person-centered.	Not included

Appendix E. Discussion of comparison of provisional labels from extant literature

Extant Source	Provisional Label and Decision	Rationale/Evidence
Model of Interaction During Feeding Persons With Severe Dementia (Athlin & Norberg, 1997)	**Responsiveness** The concept is not unique to person centered ways of interacting, but is a broad term that covers both good dementia care activities as well as those that are person centered. As defined in this way, the provisional label *responsiveness* is viewed as an overarching, higher order concept that is necessary to person centered care, but not sufficiently descriptive as the study aims require. Within the study findings, *responsiveness* is descriptively captured in the category <u>adjusting care</u>. As such, it does not detract from the inductive findings, nor does it need to be added to the developing conceptual diagram.	Defining the concept is essential to a decision about its applicability in a model of person centered care. The concept traditionally has two definitions: a) answering or replying, or b) readily reacting to suggestions, influences, appeals, or efforts. The first definition is so broad that it is less useful in the current discussion, but must be addressed as the common definition held by many. Following this first definition, all interactions representing both good dementia care and person centered care, or even mediocre care and bad care require some degree of *responsiveness*. More applicable, though, is the second definition. In this study, verbal and nonverbal events operationalizing *responsiveness* emerged from the data and were aligned with this second definition. There are likely a multitude of variations of this broad category and this data set is not exhaustive. However, the category of <u>adjusting care</u>, with its 5 codes, appears to provide a beginning operationalization of person-centered responsiveness. Multiple other data derived codes would offer additional depth to a description of general *responsiveness*, but are not exclusively or uniquely person centered (e.g. 'giving additional instruction', or 'distracting'). Both definitions above suggest that the response occurs in the presence of some stimulus. This limits the concept, making 'responsiveness' dependent on the person with dementia to provide information to which the caregiver can respond. Person centered care is understood, at least theoretically, as something beyond responsiveness. As Evans (1996) describes it, person centered care requires avoiding assumptions, centering on the one being cared

		for, assessing thoroughly, and seeking cues. These attributes reflect a much more active process that originates from the caregiver and moves *toward* the person with dementia. In some cases, because of the nature of the disease process, the information to which the caregiver responds will need to be sought out by the caregiver. This aspect is not captured in the term *responsiveness*.
Positive Person Work (Kitwood, 1997)	**Recognition** There is evidence in the data for this category, but it is not considered descriptive of or unique to person- centered caregiving interactions. No adjustments are made to the inductive findings related to this provisional label.	Described by Kitwood (1997) as "being acknowledged as a person, known by name, affirmed in his or her own uniqueness…Recognition is never purely verbal, and it need not involve words at all. One of the profoundest acts of recognition is simply the direct contact of the eyes" (page 90). With this description, several data-derived codes validate this label and begin to provide further operationalization. These include *using resident's name*, *greeting*, *complimenting*, *direct eye gaze,* and *positive, extraneous touch*. These codes are representative of good dementia care, but were not included in the compilation of uniquely person-centered codes, based on the guiding definitions and assumptions of the study and the interest in determining person-centeredness based on an integration of the critical attributes of person-centered care. For example, complimenting the person receiving care or even providing a positive touch does not facilitate freedom of choice or maximize control, although it is arguably a valuable aspect of good dementia care. These activities are a means of communicating value and respect to the person receiving care, but they are not concrete activities that avoid assumptions or accommodate needs and preferences of the person.
Positive Person Work (Kitwood, 1997)	**Facilitation** There is evidence in the data for this category, but it is not considered unique to person-centered caregiving	Kitwood (1997) defines this category of positive person work as "enabling a person to do what otherwise he or she would not be able to do, by providing those parts of the action – and only those – that are missing" (page 91). The following data-derived codes: *supporting independent activity, guiding touch, asking if resident is*

	interactions. No adjustments are made to the inductive findings related to this provisional label.	*able and willing to perform an action, facilitating, motioning the activity,* and *physically demonstrating,* as well as the multiple *informing* codes, provide validating evidence of aspects of this category. A limitation of the data set affecting the investigator's ability to fully describe or analyze this category exists in that she was unable to know whether the person receiving care was being helped more than was needed or desired. Similar to Kitwood's *Recognition* category, *Facilitation* is viewed as essential to good dementia care, but not unique to person-centered ways of caring. In that good dementia care is foundational to person-centered care, facilitating activities will be part of care that is person-centered, but the activities not exclusively person-centered.
Positive Person Work (Kitwood, 1997)	**Negotiation** Evidence of this category is present in the data. A collection of person-centered negotiating strategies emerged. However, the investigator's observation of strategies making up the <u>Negotiating Care</u> category appear to be something different than is described by Kitwood (see rationale and evidence). An alternative label and description is offered to better reflect the apparent intent of the Negotiation label, based on Kitwood's definition of	Kitwood (1997) suggests that the characteristic of this category is that the person receiving care "is being consulted about their preferences, desires, and needs, rather than being conformed to others' assumptions" (pg. 90). This definition is quite broad and supports the higher order, critical attribute of choice and autonomy identified in the guiding assumptions of the study. Kitwood's definition poorly fits the concept of negotiation, which traditionally carries a process-oriented connotation. This category and Kitwood's definition is better described by the term <u>Seeking guidance</u>, which was determined to be uniquely person-centered. Five codes emerged or were extended from the data to operationalize this category: 1) *Asking about preferences,* 2) *Looking for cues,* 3) *Asking for feedback about care,* 4) *Asking about pain and comfort,* and 5) *Asking for permission.* A primary aim of the study was to operationalize person-centered care interactions, keeping the codes and categories close to the level of the data to improve clarity of concepts. With this aim in view, two modifications to Kitwood's definition as stated is offered. A lower-level, operational definition of Kitwood's more

	Negotiation. This is captured in the subcategory Seeking Guidance. At the same time, the provisional label Negotiation was validated and is useful in the developing model. Negotiating Resistance is the label included in the model.	abstract definition follows: Seeking guidance is defined as: Verbal interaction from the caregiver that solicits information for the caregiving episode, putting the person receiving care in a position to direct the care process as much as they are able. Finally, a category of Negotiating Care does appear to be an appropriate category label, described by data-derived codes representing strategies used by caregivers in response to the person with dementia's reluctance or refusal to participate in the caregiving process. The codes emerging directly from the data supporting this category included: *affirming a dissenting response, suggesting an alternative plan in order to complete care activity for dissenting resident, affirming resident's action*, and *expressing a different perspective*. Through the use of these strategies, the caregiver demonstrates willingness to compromise, putting the resident's preferences before the priorities of the caregiver, and offering a degree of flexibility in the moment by moment process of care delivery. A process of compromise or negotiation evolves, one in which the resident is honored and common ground is pursued without violating the goals of either member of the dyad. The following data derived and theoretically-extended codes are proposed as person centered negotiating strategies: • Accepting resistance • Offering a plan B • Seeking guidance: asking about preferences, asking about pain • Expressing a different perspective • Going along or 'seeking agreement' Exemplars: 514-3, clips 21-24; 543-2-38; 534-5-22 Negative case: 534-5, clips 10-20

Positive Person Work (Kitwood, 1997)	**Collaboration** The provisional label was validated through the findings of this study, but *collaboration* is viewed as a label representative of the entire process of interaction rather than the caregiver aspect of interaction that was the focus of the study.	Collaboration, in caregiving, is a higher order concept defined by Kitwood (1997) as care that is “not something that is done to a person who is cast in a passive role; it is a process in which their own initiative and abilities are involved’ and that it requires “two or more people aligned on a shared task, with a definite aim in view” (page 90). Like all of caregiving, collaboration is an amalgam of nonverbal and verbal exchanges, involving the active participation of both members of the caregiving dyad in interaction. Because of cognitive limitations associated with dementia affecting the person receiving care, an underlying assumption of this study was that caregivers are inevitably in a position to lead each caregiving episode. Within a person-centered care model, it is the responsibility of the caregiver to share this control, and to the degree possible, join with the person receiving care to complete the tasks of morning care. Thus, this study focused on the verbal and nonverbal aspects of care as delivered by the caregiver that could be argued to be essential to person centered ways of caring. The aims of the study were less concerned with the response from the person receiving care that resulted from these activities or words. As a result, the study does not address the complete interaction cycle, which the concept *collaboration* necessitates. However, the identified person-centered caregiving interactions would clearly foster a collaborative process as defined by Kitwood. Because of this, the investigator believes this provisional label was validated through the findings of this study, but views *collaboration* as a label representative of the entire process of interaction than was the focus of the study.
Health professional-geriatric patient interaction behavior rating code (Adelson, Nasti, Sprafkin,	**Asking for feedback** There is evidence within the data to support this label, and it is determined to be unique	Defined by the authors as “gives choices, develops options for the patient, asks if something hurts or how it feels”, this low-level provisional label is well supported by the data, and was used as a code within the category describing the caregiver’s verbal content

Marinelli, Primavera, and Gorman, 1987)	to person-centered caregiving interactions.	in the study. It is representative of the loose consensus of critical attributes that define person-centered care. The data-derived definition for the code *asking for feedback* is "CG specifically asks the person receiving care for input about the process of care delivery. Often takes the form of, 'how was that?' or 'ok?' or 'How's that feel?'"
Health professional-geriatric patient interaction behavior rating code (Adelson, Nasti, Sprafkin, Marinelli, Primavera, and Gorman, 1987)	**Pacing procedure** There is evidence in the data to support the concept represented by this label, but without modification, *Pacing procedure* is not very useful as a descriptor of care because of the subjectivity of observations around this concept. Aspects of the pace of care are included in the nonverbal interaction principles developed as a result of the study.	Broadly defined by the authors as: *too fast, too slow*, or *just right.* In initial observations, the investigator intended to code the rate or pace of care delivery. However, the resulting codes were not much more refined than those above because it was incredibly difficult to describe this aspect of care in a meaningful way that was not overly subjective and could have a hope of inter-rater (or even intra-rater) reliability at some future point. At the end of observations, codes that were related to observable aspects of the timing of care delivery were: a) *hurried*, b) *late warning*, c) *calm or neutral*, d) *waiting*, e) *pausing or stopping activities*, and f) *time for extras*. While *late warnings* might seem a descriptor of a *hurried* pace, it was noted that late warnings also occurred in clips and entire episodes of care in which the vast majority of the care appeared calm or neutral. A calm and neutral caregiving pace is viewed as a fundamental aspect of good dementia care, not unique to person-centered care. This code is defined as "calm, steady pace of care delivery that is determined by the caregiver in the absence of overt indicators from the resident that care needs to be slower or quicker." This is an essential piece of the developing nonverbal principles underpinning all verbal person-centered caregiving interactions. The code *pausing or stopping activity* is defined as "caregiver

		briefly pauses or stops the activity for some reason, most often for communication with the resident." This code is believed to be part of Adjusting care, but is not uniquely person centered independent from a response to cues from the person receiving care. It is one strategy used by caregivers who are adjusting care to meet the individual needs of the resident. The code *time for extras* is defined as an "action of the caregiver suggests that he/she is allowing time for activities above and beyond the completion of the basic or required tasks. Examples would include a brief massage or putting on a watch or lipstick." Based on the concept of knowing the person, understood to be a dynamic learning process, this code may represent an aspect of person-centered caregiving. Whether or not the activities completed (the massage or putting on lipstick) are preferred by the resident or unique to the resident (e.g., the caregiver doesn't put lipstick on every female resident) is integral to determining whether the code is indeed person-centered. Because of limitations in the data set, the investigator could not know this aspect of preferences, which is based on historical knowledge. The code *waiting* is defined as a "clear instance of the caregiver slowing or stopping their activity in order to allow the resident to be independent in an activity. The caregiver doesn't move on to the next task until the resident has had a reasonable amount of time to complete the current task. The timing of resuming activity appears to be driven, in large part, by the resident." This code, as defined, is uniquely person-centered, in that the resident is ultimately guiding the pace, with the caregiver facilitating a maximal amount of control and choice for the resident. It is perhaps one of the more objective, observable manifestations of a person-centered pace.

		Ultimately, a person-centered pace is believed to flow naturally from the resulting data-derived code *following their lead* in particular. Other caregiver actions classified under the <u>Adjusting care</u> category (*stopping care activity, increasing assistance, following through*, and *trying again to get it right)*. In other words, if a CG is adjusting care, they are, by default, providing a person-centered pace.
Health professional-geriatric patient interaction behavior rating code (Adelson, Nasti, Sprafkin, Marinelli, Primavera, and Gorman, 1987)	**Pacing speech** This label was not supported by the data; no codes emerged that were aligned with the concept of the pacing or timing of the caregiver's speech. A lack of codes does not provide evidence that a person-centered pacing of speech doesn't exist, but it does suggest that observational methods prove challenging for this concept. As nonverbal principles are developed for person-centered interpersonal interaction with the person with dementia, the pacing, or rate, of the caregiver's speech is believed to be an important characteristic. Moderated or slightly slowed speech would be most valuable to the person	Broadly defined by the authors as: *too fast, too slow*, or *just right*. Even more so than 'pacing procedure', this provisional label appears most challenging to classify in a meaningful way using observational methods alone. The timing of the caregiver's speech did not arise as an aspect of care during observation by this investigator. However, on a related note, the investigator entered observations with the assumption that the tone and perhaps the volume of the caregiver's speech would have a bearing on the quality of the care being delivered. Those two categories were coded, resulting in 4 descriptors of a *positive* tone of voice after code reduction: 1) <u>Interested</u>: An engaging tone, conveys 'friendliness' or genuine interest in the resident or resident's response. 2) <u>Light-hearted</u>: Pitch may be elevated slightly, quality is not serious or intense, but conveys simplicity and ease. 3) <u>Sincere</u>: Pitch may be slightly lower and without much variability. Conveys a more serious and genuine message. 4) <u>Gentle</u>: Soft and caring quality, volume may be quieter, pitch is steady. May convey a sense of peace or soothing tenderness. The <u>Volume of speech</u> category was coded as *increased, soft or quiet*, and *normal*. As presently coded, there appears to be little value in the current codes, in part because of the inability to

	with dementia to aid in optimizing any hearing deficits and allow for latencies in cognitive processing.	determine whether the volume met the care receiver's unique hearing needs. However, while they are important, tone and volume of speech are not uniquely person-centered qualities, but they are inseparable categories within the developing list of principles of nonverbal caregiving interaction, necessary for both good dementia care and as a foundation to person-centered caregiving interactions.
On-the-job performance measures of person-centered care (Boettcher, Kemeny, DeShon, & Stevens, 2004)	**Responding to need driven behaviors** There was support for this category-level label in the data, but it is believed to be less inclusive than the more descriptive <u>Adjusting care</u> category. As worded here and described by Algase et al (1996), it is viewed as unique to person-centered care.	Defined by the authors as, "using strategies such as making reassuring statements to meet resident's immediate needs". This categorical label is drawn from the work of Algase et al, 1996 and the Need-Driven Dementia-Compromised Behaviors Model. In this model, all behaviors, particularly those that are perceived by caregivers as problematic (i.e. kicking, grabbing, yelling, or other forms of distress) are viewed as representing unmet needs that then serve as the basis for evaluation and direction of care in response to the need. Similar to the provisional label *responsiveness* from Athlin and Norberg's work (1997), this category is thought to be operationalized in large part by the data driven category <u>Adjusting care</u>, although some of the referenced need-driven behaviors may require a simple repeated instruction or the provision of more information, which are strategies that were evidenced in the data but not included in the person-centered interaction code list. When coded responses such as these (e.g, *giving additional instruction* or *repeating instruction*) were analyzed at the code-level against the guiding definitions of the study, they were not considered to be uniquely person-centered. This raises a question about the boundaries of these concepts, many of which have substantial overlap with activities and interactions thought to be encompassed by good dementia care.
On-the-job performance measures of person-centered care	**Use of unique details of resident's lives** This label was not supported by the data, but	The authors define this code as, "uses residents' preferred name and refers to unique details of their lives when referring to them." Caregivers in the analyzed videos did use residents' names, but

(Boettcher, Kemeny, DeShon, & Stevens, 2004)	a lack of evidence does not suggest that this label is not person-centered. Rather, it evidences known limitations in the data set. No determination is made about this label.	there were no instances of referring to unique details of the resident's life. The simple use of the resident's name is insufficient to fit this label or to consider it person-centered. Furthermore, it is not known whether the name the caregiver uses in the episode of care is the name by which the resident prefers to be called.
On-the-job performance measures of person-centered care (Boettcher, Kemeny, DeShon, & Stevens, 2004)	**Respecting individuality** Evidence for this label, as interpreted by the investigator, is present in the data. Aspects of *respecting individuality* must accompany the identified verbal interaction strategies. As such, the principles of *respecting* individuality work in tandem with the categories of *Seeking guidance, Clarifying ambiguity, Negotiating resistance, Validating satisfaction and Adjusting care.*	The term *respecting individuality* is subjectively interpreted and the definition remains quite broad as well. The authors define this code as "using nonverbal behaviors when initiating an interaction with a resident that demonstrate respect for the resident's individuality." The authors do not provide further operationalization of *nonverbal behaviors* or *demonstrate respect*. Clarification of the non-verbal behaviors that demonstrate respect for the resident's individuality was an expected outcome of the current study. To that end, emerging codes and subsequent analysis led to a proposed combination of nonverbal behaviors that, when used together, define this *respecting individuality* label. These are as follows: 9. When care is underway, the pace of care is calm, allowing for the resident to respond either verbally or physically. The caregiver waits, as needed, accommodating to the resident's speed of task completion or communication. 10. Caregiving activity is paused or stopped when a) asking the resident about pain, b) apologizing for causing discomfort, or c) in response to any form of resistance from the person receiving care. 11. When the caregiver speaks, the tone of voice is positive and appropriate to the situation. The four resulting descriptors of positive tone follow: 1) Interested: An engaging tone, conveys 'friendliness'

		toward the resident and interest in the resident's response. Content may include asking questions. 2) <u>Light-hearted</u>: Pitch may be elevated slightly, quality is not serious or intense, but conveys simplicity and ease. Content may include humor or banter. 3) <u>Sincere</u>: Pitch may be slightly lower and without much variability. Conveys a more serious and genuine message. 4) <u>Gentle</u>: Soft and caring quality, volume may be quieter, pitch is steady. The tone conveys a sense of peace or soothing tenderness. 12. <u>Volume of speech</u> reflects the patient's needs, adjusting to hearing impairment or latencies in cognitive processing. 13. When not involved in a caregiving task that requires focused attention, the <u>eye gaze</u> is focused on the resident's face, attempting eye contact. 14. <u>Facial expression</u> is neutral or positive (friendly). 15. <u>Body orientation</u> is toward the resident whenever possible, attempting to get at eye level when appropriate, i.e. talking to the resident. Crouching is preferred over leaning from the waist. 16. <u>Touch</u>, if present, does not elicit a negative reaction from the resident. Exemplars: 543-2-33, 543-2-38, 543-2-48, 514-3-8, 514-3-15, 534-5-22
On-the-job performance	**Encouraging independence**	The authors provide the following operational definition: "uses

measures of person-centered care (Boettcher, Kemeny, DeShon, & Stevens, 2004)	Evidence of this label as defined by the authors is present in data set, but is not viewed as uniquely person-centered. Instead, aspects of care that generally encourage independence are part of good dementia care.	both verbal and nonverbal behaviors that are designed to initiate residents' performance of tasks that may be completed independently once begun." This is similar to Kitwood's (1997) broader term, *Facilitation*, and the codes evidencing the term also provide evidence for this label. (See rationale for *Facilitation*). Using the definition and critical attributes of person centered care that guided the study, these activities are not considered unique to person-centered ways of caring. Instead, they are argued to be essential to good dementia care, and in that good dementia care is foundational to person-centered care, facilitating activities, including *Encouraging independence* will be part of person-centered care, but are not exclusively person-centered.

Appendix F. Refined nonverbal interaction codes, definitions and classifications

Nonverbal SubCategory	**Descriptive Code**	**Code Definition**	**Classification**
Eye Gaze			
	Direct	CG makes direct eye contact with resident who is looking back at the CG.	Positive, necessary for person-centered caregiving interactions
	Focused on the activity	CG's eyes are focused directly on the activity at hand.	Neutral
	Glancing	During the course of activity, the CG momentarily looks at the resident's face	Positive, necessary for person-centered caregiving interactions
	Looking at resident's face	Looking at resident's face, often when resident has eyes closed, waiting for a response or cue. Different from 'direct' in that 'direct' means eye contact has been made. Different from 'watching' in that 'watching' refers to the CG watching the resident perform and activity or movement, not necessarily looking at the resident's face.	Positive, necessary for person-centered caregiving interactions
	Watching	While resident performs some activity, CG watches resident, often standing at the resident's side.	Positive, necessary for person-centered caregiving interactions
	Unable to observe	Position of CG or camera angle prevents viewing of CG eye gaze	Neutral
Facial Expression			
	Negative	CG facial expression conveys a negative emotion, such as disgust, irritation, or frustration	Negative

	Neutral	CG expression is bland or appears to be focused solely on the task at hand. Neither positive or negative.	Neutral
	Positive	CG expression is friendly or smiling	Positive, necessary for person-centered caregiving interactions
	Unable to observe	CG position or camera angle prevents viewing of CG face	Neutral
Purpose of gestures			
	Directional guidance	Use of the hands with an apparent intent to direct or guide the resident in some direction. May be in conjunction with words or not. An example would be motioning to the resident to move forward by placing palms up and moving fingers toward CG body.	Positive, associated with good dementia care
	Motioning the activity	CG uses hand motions to demonstrate the action the resident should take. For example, CG might put his hand to his teeth as if holding a toothbrush, moving his hand up and down.	Positive, associated with good dementia care
	Showing an object	Without words, CG communicates to resident by showing them an object, such as showing a bra to indicate that it's time to put on this article of clothing.	Positive, associated with good dementia care
Pacing			
	Hurried	For example, no pause or attempt to wait for the resident to act on instruction before beginning to assist resident, or no pause or	Negative

		waiting for a response to a question to the resident, CG moves forward with task.	
	Late warning	In conjunction with providing instruction or information to the resident, the caregiver moves ahead with the activity before the resident has time to respond	Negative
	Neutral	Calm pace, appears to accommodate needs of resident as movements are made.	Positive, necessary for person-centered caregiving interactions
	Pausing activity	CG pauses activity briefly for some reason. Could be for communication with the resident.	Positive, in context. Potentially necessary for person-centered caregiving interactions
	Time for extras	Action of the caregiver suggests that he/she is allowing time for activities above and beyond the completion of the task.	Positive, necessary for person-centered caregiving interactions
	Waiting	Clear instance of the CG slowing or stopping activity in order to allow the resident to be independent in an activity.	Positive, necessary for person-centered caregiving interactions
Spatial Relationship	Away from resident	During the activity, the CG is oriented away from the resident. Usually the CG's back is turned to the resident or the CG appears to be out of the room altogether.	Neutral
	Entering intimate space	During the course of activity, CG's face is an intimate distance from the resident's face.	Neutral
	Toward resident	During the course of activity or interaction, the orientation of the CG is facing the	Positive, potentially necessary for person-centered care

		resident, not just turned toward the resident's face.	
Purpose of Touch			
	Caregiving related	While in process of a caregiving task, CG is touching the resident. May be touching an article of clothing that is on the resident or placing a blanket on the resident, or may be actually touching the resident's body more directly.	Neutral
	Coercing	CG demonstrates persistence and some 'muscling' to override resident's resistance.	Negative
	Extraneous	Any hands-on contact by the CG to the resident that is not directly related to completion of an activity. May be a pat on the back, or resting of the hand on the shoulder.	Neutral
	Guiding	By the touch, which may be very light, the resident is directed toward some activity, such as starting to hold a brush, or CG hand on resident's arm to lead them in a certain direction.	Positive, associated with good dementia care
	Insensitive	A caregiving related touch, but the timing of it seems overtly insensitive. For example, the CG washes the resident's eye at the same time the resident is making direct eye contact with the CG and verbally responding to a question from the CG. Uses sufficient pressure in the process to make the resident close her eye tightly.	Negative
	Stopping	CG touches resident's hands	Potentially negative,

	resident's movements	in an effort to stop their movement or distract them from their activity - could be in order to get the resident's attention, move them on from a perseverating behavior, etc.	situation specific
Volume of Speech			
	Increased	In comparison to previous exchanges within the episode of care, volume is louder	Neutral
	Normal	Conversational, appropriate for most situations	Neutral
	Soft	Quiet speech, may seem as if CG is talking to self	Neutral
Tone			
	Perfunctory	Automatic or mechanical. Impersonal feel. May occur when caregiver continues talking even though it appears the resident is fully disengaged either because he/she is sleeping or otherwise distracted	Negative
	Matter of fact	Simply the facts - Business-like, limited in emotion	Neutral
	Gentle	Soft and caring quality, volume may be quieter, pitch is steady. Conveys a sense of peace or soothing tenderness	Positive, associated with good dementia care
	Sincere	Pitch may be slightly lower and without much variability. Conveys a more serious and genuine message.	Positive, associated with good dementia care
	Light-hearted	Pitch may be elevated slightly, quality is not serious or intense, but conveys simplicity and ease.	Positive
	Interested	An engaging tone, conveys 'friendliness' or genuine interest in the resident or resident's response.	Positive, potentially necessary for person-centered care

Appendix G. Person-centered caregiving interaction glossary

Category	Person Centered Strategy	Person-Centered Definition
<u>Seeking Guidance</u>: This is understood as those active processes, both verbal and nonverbal, (as in the case of 'looking for cues'), in which the caregiver solicits information for the current caregiving episode, putting the person receiving care in a position to direct the care process as much as they are able.		
	Looking for cues	During the process of completing tasks or independent activities, the caregiver looks at the face of the person receiving care. <u>Data-based exemplars</u>: While the resident is walking, the caregiver watches him closely, looking both at his face and body as he does so. During incontinence care, the caregiver glances several times at the person's face.
	Asking about preferences	Asking the person receiving care about their first choice in care activities (e.g., the sequence of activities, how a transfer is done) and the range of choices that occur during each care episode (e.g., clothing items, buttoning a sweater or leaving it unbuttoned). <u>Theoretical example</u>: A caregiver who is asking about preferences may say something like, "Helen, would you like to get dressed sitting in your chair?" or "Would you like to wear lipstick today?"
	Asking about comfort and pain	Either as a course of interaction or in response to some indication by the person receiving care, the caregiver asks the person receiving care about their comfort level, as well as asking directly about pain, as specifically as possible. <u>Theoretical example</u>: A caregiver asking about pain may say something like, "Is your shoulder hurting today?" or "I know your hip hurts sometimes. Before I help you get out of bed, I want to know if it's bothering you today."
	Asking permission	Before initiating any care activity that requires hands-on assistance from the caregiver, the caregiver asks the person receiving care if he/she is ready to begin the process. <u>Theoretical example</u>: A caregiver 'asking permission' will most often combine the question with information for the person receiving care. For example, the caregiver may say, "Next, we need to put your shirt

		on. Are you ready?" Or, at the beginning of care, "I'm here to help you get ready for the day. Is it ok to get started?"
	Asking for feedback	Asking the person receiving care about their perception of the delivery of care. Theoretical example: A caregiver who is asking for feedback may say something like, "How did we do getting you into the chair?" or during the process of getting dressed, "Is this going ok for you?"
Validating Satisfaction: This includes those activities that assist the caregiver in knowing that they are meeting the care-receiver's needs and preferences		
	Looking for cues	See definition and example above
	Asking for feedback	See definition and example above
Clarifying ambiguity: includes verbal interaction from the caregiver that assists the caregiver in optimizing all forms of communication from the person receiving care, especially those which leave the caregiver uncertain. In doing so, the caregiver reduces the likelihood of making assumptions about the communication.		
	Checking the meaning of cues	When the person receiving care displays a behavior, utters an unintelligible word or phrase, or vocalizes (e.g., moan), the caregiver asks directly about it, seeking to confirm or contradict his interpretation of the behavior, words, or vocalization. Data-based exemplar: The person receiving care is waiting, without a blouse on, for the caregiver to help with upper body dressing. She begins a stuttering, unintelligible vocalization. The caregiver says, "Come on and hurry up, right?", asking the person receiving care if she is interpreting the vocalization correctly.
	Clarifying responses	When the person receiving care responds to a question generally or makes a comment that is general in nature, the caregiver asks additional questions in an effort to clearly understand the person receiving care. Data-based exemplar: Person receiving care is standing, commenting about her pants. She says, "It's a little bit too long now." The caregiver, clarifying her comment, asks, "Where, down here?" as he crouches down next to her feet. The person receiving care responds, "Hmm mmm."

	Trying again for input	When the person receiving care has not responded to a question from the caregiver, the caregiver asks the question again, or asks for the information in a different way, making sure the person heard the question and was focused on the content. Data-based exemplar: Caregiver asks the person receiving care if he would like to wear his hat and he did not respond, she makes eye contact, speaks in a volume he can hear, and says, "Gary, I'd like to know if you'd like to wear your hat today?"
Adjusting Care: An active response by the caregiver to new information from the person receiving care. This information may come by way of a corrective action, a comment or request, or some behavioral or vocal cue. The caregiver then attempts to incorporate the new information into the way he/she assists during the caregiving episode.		
	Following their lead	In response to an active cue from the person receiving care, the caregiver changes his/her immediate actions in order to verbally or physically assist the person receiving care. Data-based exemplar: The caregiver is nearby, preparing items for brushing teeth while the person receiving care is using the toilet. The person receiving care finishes and begins to stand before the caregiver is ready. The caregiver switches from the prep task to an assisting task, guided by the actions of the person receiving care.
	Increasing verbal or physical assistance	In response to an active or verbal cue from the person receiving care, the caregiver makes an adjustment to the way care was being delivered and increases the amount of hands-on assistance or offers more specific verbal cues so that the care receiver can complete the activity. Data-based exemplar: The person receiving care is attempting to put on her shirt independently. The caregiver is nearby, drying off the sink. The person begins having trouble getting her head through the shirt and is stuck. The caregiver provides hands-on assistance for completing the upper body dressing, talking through the aspects of the task.
	Stopping care activity	In response to some behavioral or verbal/vocal cue from the person receiving care, the caregiver stops their activity. The time-frame for

		stopping care may vary. A simple pause may be sufficient in some cases; other circumstances may lead the caregiver to stop the activity in order to enter into negotiating care, or even to end the caregiving altogether in order to come back another time. <u>Data-based exemplar:</u> a caregiver is attempting to lead the person receiving care to the sink to wash her face. The person pulls away from the caregiver and begins vocalizations with a negative tone. The caregiver stops the attempt to lead and turns toward the person receiving care.
	Following through	In response to verbal expressions of need or preference, or action behaviors with a clear intent, the caregiver acknowledges the information and informs the person receiving care how he/she will address the information. ‘Following through’ also includes some action that indicates the caregiver is acting on the information received. <u>Data-based exemplar:</u> The person with dementia indicates by action and attempted speech that she would like help with rolling up her sleeves. The caregiver says, “I can help you with that”, and begins doing so, offering to do the second sleeve as well.
	Trying again to get it right	In response to a behavioral or verbal/vocal cue of dissatisfaction or discomfort during a specific caregiving task, the caregiver performs the same task differently, repeating with slight adjustments to the action until the cues or feedback indicate satisfaction. <u>Data-based exemplar:</u> The person receiving care voices dissatisfaction with how her pants look and feel. The caregiver makes a couple of very slight adjustments to the way the pants sit at her waist until she indicates it is the way she prefers.
<u>Negotiating Resistance:</u> The caregiver’s person-centered response to any degree of reluctance, resistance, or expressed dissatisfaction to the caregiving process by the person receiving care.		
	Accepting resistance	Verbally acknowledging and respecting the expressed reluctance or resistance of the person receiving care. In so doing, the caregiver creates an environment of non-resistance, choosing to meet resistance with acceptance rather than more resistance.

		Data-based exemplar: In response to the resident’s firm “no” when asked if he was ready to get out of bed, the caregiver responds with a simple, “Ok”, pausing all activity.
	Offering a plan B	As part of the negotiating process, the caregiver suggests an alternative to the current course of care. Data-based exemplar: After accepting the recognized resistance in the above example, the caregiver says, “Why don’t we try again in a few minutes?” She remains by his bed, makes eye contact, and gently massages his knee. There is no further resistance.
	Offering different perspectives	Within a process of negotiation, the caregiver offers his/her perspective of the situation. The intent is to move the person receiving care past a point of perseveration so that care can move ahead. Data-based exemplar: A resident is expressing concern that her outfit “Is just not right”, and has trouble moving past this concern. The caregiver offers a genuine compliment about the resident’s appearance which appears to reassure the resident. Care resumes.
	Going along	At the end of the process of negotiating, the caregiver defers to the person receiving care, either asking for permission to move forward with the negotiated new plan or simply beginning to act on the plan indicated by the person receiving care. Data-based exemplar: In response to the caregiver’s offering a plan B to wash the resident’s face in bed instead of at the sink, the resident begins getting back in bed. The caregiver ‘goes along’, beginning to act on the new plan.
Respecting Individuality: The nonverbal context of caregiving interaction demonstrating a value of the person’s uniqueness and humanity. Eight principles resulted from analysis of the caregiver’s nonverbal interaction codes.		
1. When care is underway, the pace of care is calm, allowing for the resident to respond either verbally or physically. The caregiver waits, as needed, accommodating to the resident’s speed of task completion or communication. 2. Caregiving activity is paused or stopped when a) asking the resident about pain, b) apologizing for causing discomfort, or c) in response to any form of resistance from the person receiving care. 3. When the caregiver speaks, the tone of voice is positive and appropriate to the situation. The four resulting		

descriptors of positive tone follow:

1) Interested: An engaging tone, conveys ‘friendliness’ toward the resident and interest in the resident’s response. Content may include asking questions.

2) Light-hearted: Pitch may be elevated slightly, quality is not serious or intense, but conveys simplicity and ease. Content may include humor or banter.

3) Sincere: Pitch may be slightly lower and without much variability. Conveys a more serious and genuine message. 4) Gentle: Soft and caring quality, volume may be quieter, pitch is steady. The tone conveys a sense of peace or soothing tenderness.

4. Volume of speech reflects the patient’s needs, adjusting to hearing impairment or latencies in cognitive processing.
5. When not involved in a caregiving task that requires focused attention, the eye gaze is focused on the resident’s face, attempting eye contact.
6. Facial expression is neutral or positive (friendly).
7. Body orientation is toward the resident whenever possible, attempting to get at eye level when appropriate, i.e. talking to the resident. Crouching is preferred over leaning from the waist.
8. Touch, if present, does not elicit a negative reaction from the resident.