

THINGS THAT MATTER TO RESIDENTS IN NURSING HOMES AND THE
NURSING CARE IMPLICATIONS

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Submitted to the faculty of the University Graduate School
in partial fulfillment of the requirements
for the degree
Doctor of Philosophy
in the School of Nursing,
Indiana University

June 2014

Accepted by the Graduate Faculty, Indiana University, in partial fulfillment of the requirements for the degree of Doctor of Philosophy.

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DEDICATION

This dissertation is dedicated to residents who experience the transition into nursing homes, their families who endure deep-hearted sentiments when their loved ones live in nursing homes, and nurses who render care with passion and authentic presence that reach the hearts of residents.

ACKNOWLEDGEMENTS

This has been a remarkable journey and I am deeply grateful for the many people who contributed to my completion of this process.

First, I am blessed to have my supportive and understanding husband, Randy, who has always been by my side. His unending love and support provided me with confidence to accomplish my goals during this work.

Secondly, my children and grandchildren provided never-ending love and admiration that enriched my dream that they, too, will find such reward in their future educations and life experiences.

My parents were unendingly supportive and loving. Their guidance assisted me to develop curiosity about meaning in life and a spirit of inquiry.

I am so privileged to have the following committee members: Dr. Sara Horton-Deutsch, Dr. Carol Baird, Dr. Daniel Pesut, and Dr. Pamela Ironside assist me in completing this process. Having these inspirational scholars and researchers lead me during this process was truly an honor. I could not have completed this process without their support and guidance.

I would like to extend a very special recognition to my chair, Dr. Sara Horton-Deutsch, who motivated me to reflect on my goals for exploring what was important to residents in nursing homes. Her foresight provided me with self-awareness and determination to find the research method that best fit my research topic. Her guidance has inspired me to value a deeper meaning of inquiry and a lifelong pursuit of knowledge.

One of my mentors, Dr. Carol Baird, has been an inspiration during my learning experience. Her geriatric expertise was extremely helpful as she guided me throughout the entire research process. Her endless support was most meaningful. She provided me with essential feedback and shared my desire for continual learning about care of older persons.

I also would like to thank Dr. Daniel Pesut who motivated me to explore complexity principles and seek for deeper meaning of situations. I value his intellectual questioning approach that led me to think differently about relationships of concepts in my research. Because of his profound insight about the complementary nature of aspects, I developed a newfound ability to appreciate complexity and seek for creative resolutions of situations.

I am eternally grateful for Dr. Pamela Ironside's expertise in qualitative methods that enhanced my understanding and appreciation of qualitative research. She provided me with tools to transform my thinking and to seek for deeper understanding about things that matter to residents. I found her repeated message, "May the wind be in your sails!" uplifting, and it instilled me with confidence to continue moving forward with my work. Learning from her expertise in nursing education and view of interpretive scholarship inspired me to find new ways to conceptualize my roles as a nurse educator and new researcher.

Dr. Margarete Sandelowski, an expert researcher from the University of North Carolina at Chapel Hill School of Nursing, also contributed to my in-depth understanding of qualitative research methods. I am eternally grateful for the opportunity to learn from

Dr. Sandelowski's extensive research knowledge that enhanced my understanding of qualitative research methods and rigor.

In addition, I would like to thank the faculty and staff of Indiana University School of Nursing, including Dr. Marsha Ellett and Dr. Rebecca Sloan, who also guided me in understanding qualitative research methods. I am grateful for the opportunity to partake in their group discussions that expanded my knowledge and understanding of the iterative process used in qualitative research. I would also like to thank Debbie Grew and Debra Barker who have continued to guide me in finalizing my work. As well, I would like to extend a special thank you to Cynthia Hollingsworth whose editing expertise has been incredible.

I would also like to thank my cohort of PhD colleagues who collectively became *The Transformers*. I am honored to have become acquainted with each one of the cohort and specifically my very close friends, Dr. Sue McManus and Dr. Jane Tiedt. We engaged in many hours of hard work and yet, fun times that will become special memories.

I would like to thank my colleagues at Indiana University–Purdue University Fort Wayne including Dr. Carol Sternberger and Dr. Linda Meyer for their high expectations within nurse educator and researcher roles; Dr. Susan Ahrens for her creativity and expertise in qualitative research; and Dr. Linda Finke for her expertise in research writing and representation. Each of them has uniquely contributed to my success in completing this work.

In conclusion, I would like to thank Mr. Gary Graham and Mrs. Jane Graham for accepting my nomination by Dr. Carol Sternberger for the Kelly Graham Faculty

Scholarship award. I would like to also thank Dr. Ann White and the Indiana League of Nursing for the generous scholarship. These funds assisted me with completing my study.

Nila B. Reimer

THINGS THAT MATTER TO RESIDENTS IN NURSING HOMES AND THE
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A move toward care of residents in nursing homes where they are respected and heard is finally emerging. Common strategies used in nursing homes to improve quality of care for residents are integration of person-centered care and assessing care using satisfaction surveys. Although approaches of integrating person-centered care and satisfaction surveys have been valuable in improving nursing home quality, strategies of care that include things that matter from residents' perspectives while living in nursing homes need investigation. The purpose of this qualitative descriptive study was to describe things that residents age 65 and older state matter to them while living in the long-term care sections of nursing homes. A qualitative mode of inquiry using purposeful sampling led to a natural unfolding of data that revealed things that mattered to residents. Content analysis was used to reduce the data in a manner that kept the data close to the context yet moved the data toward new ideas about including things that mattered to residents in nursing care. The findings revealed residents' positive and negative experiences and addressed the question: How can nurses manage residents' positive and negative aspects of care in nursing homes? This study substantiated the importance of developing nursing care strategies derived from residents' descriptions of care. Finding ways to promote nurses' investment in attitudes about a person-centered care philosophy is essential for successful person-centered care implementation. Enhancing nurses' knowledge, skills, and attitudes with an investment in person-centeredness will be more

likely to put nurses in a position to role-model care that is person-centered from residents' perspectives.

Sara L. Horton-Deutsch, PhD, RN, Chair

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ABBREVIATIONS

Abbreviation	Term
AACN	American Association of Colleges of Nursing
ACES	Advancing Care Excellence for Seniors
AHRQ	Agency for Healthcare Research and Quality
CMS	Centers for Medicare and Medicaid Services
CNA	Certified Nursing Assistant
IOM	Institute of Medicine of the National Academies
IRB	Institutional Review Board
LPN	Licensed Practical Nurse
MDS	Minimum Data Set
MDS-Cogs	MDS-Cognition Scale
MoCA	Montreal Cognitive Assessment
NLN	National League for Nursing
RN	Registered Nurse
USDHHS	United States Department of Health & Human Services
USGAO	United States Government Accountability Office

CHAPTER ONE. INTRODUCTION

A move toward care of residents in nursing homes where residents are respected and heard is finally emerging. Nursing home care has continued to improve according to the United States Government Accountability Office (USGAO, 2005). In addition, a more clear understanding about ways to accurately assess and render higher quality of care have emerged within regulatory guidelines for nursing homes (IOM, 2001b). Ideal nursing homes require their staff members to provide residents the right to direct and participate in the design of their own care (Koren, 2010). While quality of care has improved in many nursing homes with the number of survey citations decreasing by 1% between 2009 and 2011 according to the United States Department of Health and Human Services Centers for Medicare and Medicaid Services (USDHHS CMS, 2012a), concern about poor quality of care continues to exist in other nursing homes (Commonwealth Fund, 2014; IOM, 2001b; Koren, 2010; USDHHS CMS, 2014c; USGAO, 2012). Even though nursing home care has continued to improve over the last decade, up to 48% of nursing homes nationally have deficiencies in quality of care (Commonwealth Fund, 2014).

Although there has been progress in quality of care in nursing homes, it is discernible that nursing caregivers continue to miss things that matter to residents in their care. As a nurse and nurse educator with experience caring for residents in nursing homes, I believe that for the most part nursing caregivers have good intentions to render quality care for residents. However, nursing caregivers' ideas of what is important in quality care may be incongruous with things that matter to residents during their care while living in nursing homes.

Background, Significance, and Nursing Research Priorities

According to the United States Census Bureau, 20% of the population in the United States will be aged 65 or older within the next 40 years (He & Muenchrath, 2011). Between the years 2020 and 2030, the population aged 65–89 is expected to increase 32% and aged 90 and over is expected to increase 21% (He & Muenchrath, 2011). The USDHHS National Institute on Aging (2011) projected that the oldest-old population, aged 85 and older, will increase 151% globally by year 2030. The most rapidly growing segment of the overall population is persons aged 90 and over. Persons in this oldest-old segment of the population are most likely to require long-term care (USDHHS National Institute on Aging, 2011). Approximately 4% of all persons who are aged 65 and older (American Association of Retired Persons, 2008), or 1.5 million Americans overall (USDHHS Centers for Disease Control and Prevention [CDC], 2012c), reside in nursing homes. Twenty percent of the overall population aged 85 or older resides in nursing homes, and approximately one-half of residents in nursing homes are aged 85 and older. There are few residents below the age of 65. Most residents in nursing homes are single women (72%) who are widowed, divorced, or never have been married (American Geriatrics Society Foundation for Health in Aging, 2012).

With the predicted increase in the population of older persons, the IOM committee's report, "Retooling for an Aging America" (2008), suggested that by 2030 healthcare providers will need to improve their knowledge and skills for meeting the healthcare needs of older persons over the age of 65. The IOM advocates enhancement of geriatric competence for the entire workforce and an increase in the recruitment and retention of geriatric specialists and caregivers who will improve the care of older

persons (IOM, 2008). Historically, much investigation in quality of care in nursing homes has revealed a serious need for improvement (Arling, Kane, Mueller, Bershadsky, & Degenholtz, 2007; Flesner & Rantz, 2004; Goodson, Jang, & Rantz, 2008; IOM, 2001a, 2001b) even though a focus on quality of care has improved overall in nursing homes during the last decade (IOM, 2001b; USDHHS CMS, 2012a). As a result of a major reform initiated by the IOM in 1987, nursing home care improvement has occurred in areas of restraints, care planning, nutrition, and consumer access to quality of care information (IOM, 2001b). Nevertheless, during 2006, nearly one out of five nursing home state surveys in the United States revealed serious deficiencies that reflected actual harm or potentially serious harm to residents (Nursing Home Reform, 2007). During year 2009, deficiencies that caused harm to residents were found in 755 nursing homes in the United States and 195 of these deficiencies placed residents at risk for serious harm or death (USGAO, 2009). In addition, representatives of the Kaiser Family Foundation reported ongoing concern about care of residents in nursing homes that lead to their hospitalizations (Perry, Cummings, Jacobson, Neuman, & Cubanski, 2010).

Quality of nursing home care continues to be a rising concern (Castle & Ferguson, 2010; Koren, 2010; Misiorski, 2011; Werner & Konetzka, 2010; USGAO, 2012). The USDHHS Agency for Healthcare Research and Quality (AHRQ) revealed an innovation presented by Boyd and Mitchell (2012) who addressed concerns as a result of nursing homes utilizing a traditional model of care similar to the medical model of care used in hospital-type organizations. Problems that currently exist with the traditional model of nursing home care include: (a) staff members treating residents as patients, which results in a culture of dependency for residents; (b) residents living in an institutional

environment with characteristics such as long halls that seem uninviting; (c) residents' fear of reporting concerns or problems; and (d) high employee turnover rates (Boyd & Mitchell, 2012). In addition to these problems, there is a growing concern about the ability for nursing home staff members to handle residents' increasing complex disabilities (Corazzini, Anderson, Mueller Thorpe, & McConnell, 2013). The government's recent shift to implement community-based programs to keep patients in their homes has caused nursing homes to admit residents with higher acuity levels; therefore, residents require more intense care compared to previous years. The future complexity of nursing home care will add to the need to increase the number of ideal nursing homes where residents maintain control in their care. Care of residents that reflects things which residents state matter to them in nursing homes may provide assurance that residents are exercising self-determination, which is a right of all residents in nursing homes according to the code of federal regulations for long-term care facilities (Requirements for States and Long Term Care Facilities of 1989; Wiener, Freiman, & Brown, 2007).

Suggestions for improving quality in nursing homes include giving residents choice and participation in personal care and transforming the nursing home culture to less institutionalized environments for residents (Doty, Koren, & Sturla, 2008). Open- and extended-hour dining room service, 24-hour visitor privileges, and autonomy in choosing bathing plans are common strategies used in person-centered care and resident-directed care that have made strides in improving nursing home care (Crandall, White, Schuldheis, & Talerico, 2007; Flesner & Rantz, 2004; Robinson & Gallagher, 2008). Qualities of "ideal" nursing homes include providing residents with choices and

collaborative decision-making within care environments called “small households that are more like home,” supporting close relationships with family and staff, and assuring staff empowerment and continual quality improvement (Koren, 2010, p. 313). Other strategies recently used to improve nursing home care include cross-training staff members so that they get to know residents and replacing traditional nurse’s stations with open resident care areas called *neighborhoods* (Boyd & Mitchell, 2012). Assuring that staff members in nursing homes include elements that residents determine matter during their care seems to be consistent with care rendered to residents in ideal nursing homes.

The shift toward improving quality in nursing homes by implementing person-centered care has intended to change the philosophy of care from nurses performing care tasks to nurses promoting residents’ satisfaction, empowerment, personal growth, and connection to the community (Flesner & Rantz, 2004) and centering care on the person (Degenholtz, 2013; Robinson & Gallagher, 2008). Koren (2010) included the integration of person-centered care as a key component in providing respect for residents’ rights and enhancing quality of life and quality of care. Integrating principles of person-centered care includes providing residents with choice and control as well as self-determination (Flesner, 2009). However, Koren (2010) posited that most nursing home caregivers have struggled with integrating person-centered care that is congruent with residents’ preferences.

In order to improve quality of care in nursing homes, representatives of the Advancing Excellence in America’s Nursing Homes (2012) deemed it necessary to examine residents’ perspectives of their experiences while living in nursing homes. Performing research in nursing homes may improve understanding of what reflects

quality from residents' perspectives, thereby advancing methods and means of planning, organizing, and directing nursing care in more intentional person-centered ways.

Although there is a need for research for understanding residents' perspectives of quality care, there has been extensive use of satisfaction surveys for examining residents' perspectives of care in nursing homes. The literature reveals 86% of nursing homes use resident satisfaction surveys as the major source of measurement to improve quality of care in nursing homes (Castle, Lowe, Lucas, Robinson, & Crystal, 2004; Robinson, Lucas, Castle, Lowe, & Crystal, 2004). The CMS included resident satisfaction measurements in its initiatives to improve quality in nursing homes and to assess outcomes for reimbursement based on pay-for-performance (Briesacher, Field, Baril, & Gurwitz, 2009). Although studies reflect that resident satisfaction surveys have led to improved quality in nursing homes, concerns have existed about how satisfaction survey results are used in nursing homes (Castle et al., 2004; Chou, Boldy, & Lee, 2003; Rahman & Simmons, 2007). There is lack of residents' input that accurately defines variables associated with residents' satisfaction (Rahman & Simmons, 2007). Castle et al. (2004) also found the primary use of satisfaction surveys was for administrative purposes such as marketing versus improving quality in nursing homes.

Because of problems with satisfaction surveys, there is a move to improve the accuracy of these surveys in nursing homes. Members of the Advancing Excellence Campaign, a coalition of long-term care and medical professionals, governmental agencies, and consumers, collaborated with the USDHHS CMS as a result of their concern that residents' perspectives of quality may be missing in nursing home satisfaction surveys. The campaign members led the implementation of quantitative

resident satisfaction surveys that included additional assessment components for understanding what is satisfying to residents (Advancing Excellence in America's Nursing Homes Campaign, n.d., "Implementation Guide: Goal 7") campaign. In addition, the National Research Corporation's satisfaction survey (2012) that reflects customer and employee satisfaction in nursing homes was designed to capture more than resident and family member satisfaction. Quality of life, quality of care, and quality of services that reflect employee engagement and resident experiences in nursing homes are becoming more evident in the satisfaction surveys used in nursing homes (National Research Corporation, 2012; USDHHS AHRQ, n.d.). Although the literature reveals a need for improving care in nursing homes, it is interesting that the 2011–2012 satisfaction survey results released by the National Research Corporation revealed that 87% of family members and 89% of residents rated their nursing home as "excellent or good places" to receive care (National Research Corporation, 2012, p. 12).

The outcomes of this study offer insight for improving gerontological care and nursing education in support of the Recommended Baccalaureate Competencies and Curricular Guidelines for the Nursing Care of Older Adults (American Association of Colleges of Nursing [AACN], 2010b). These guidelines were added to the core competencies described in the Essentials of Baccalaureate Education for Professional Nursing Practice for ensuring that nursing education includes ethical care which provides autonomy and non-coercive decision-making for older patients and their families in their curricula (AACN, 2010c). The Graduate Essentials reveal an emphasis on advanced skills that are needed by nurses to lead ethical care that embraces the concerns of patients (AACN, 2010d). The recommended competencies serve as guidelines for nursing

programs as they develop and revise their curricula in order to prepare nurses to meet the demands of complex care needed for the growing older population (AACN, 2010a).

The study findings were in juxtaposition with the National League for Nursing's (NLN) Advancing Care Excellence for Seniors (ACES) project. The NLN along with the Community College of Philadelphia, Laerdal Medical, Independence Foundation, and John A. Hartford Foundation developed the ACES project for educating students about care of older persons (Tagliarene, Cline, Mengel, McLaughlin, & King, 2012). Insight about the need to improve gerontological content included a focus on three knowledge domains of the ACES project: individualized aging, complexity of care, and vulnerability of transitions that should be included throughout nursing program curricula.

The few studies found in the literature about things that matter to residents in nursing homes involved residents' quality of life in nursing homes (Burack, Weiner, Reinhardt, & Annunziato, 2012) and satisfaction measures (Ghusn, Hyde, Stevens, Hyde, & Teasdale, 1996; Kane et al., 1997). Additional insight for what matters to residents may lead to developing actions that enhance living in nursing homes for residents. Permitting older persons to share life stories about "things that matter" provide opportunities for older persons to gain new understanding and creative expression (Carlsen, 1991, p. 155). Things that matter to older persons provide them with purpose and significance in their lives (Carlsen, 1991). Nursing caregivers' capturing things that matter to residents while living in nursing homes is one way to add to the state of the science for understanding person-centered care, improving resident satisfaction assessments, and enhancing essential concepts of care in gerontological nursing education.

Problem Statement

Although some improvement in quality of care has occurred as a result of using person-centered strategies and resident satisfaction surveys, further improvements are needed in quality of nursing home care (Castle & Ferguson, 2010; Koren, 2010; USGAO, 2012; Werner & Konetzka, 2010). Learning about things that matter to residents may provide new ideas about ways to render care and add clarity to understanding residents' viewpoints of quality of care. Including things that matter in resident care may expand on person-centered care strategies and improve ways of assessing resident satisfaction. Despite the focus on quality improvement in person-centered strategies and satisfaction assessments, there is a lack of research about nursing caregivers' capturing things that residents describe which matter to them while living in nursing homes. Even though nursing caregivers may believe that they render quality care, they may be unaware of or overlook things that matter to residents during their care. The AACN (2010b) reported that most nursing programs need to add gerontological/geriatric content in their curricula in order to adequately prepare students to meet standards of best practice for the exploding number of individuals in the older population. Including a focus on residents receiving care that includes things that matter to them in nursing homes is consonant with the AACN's guidelines (2010a, 2010b).

Purpose

The purpose of this qualitative descriptive study was to gain knowledge about what things matter to residents aged 65 and older in the long-term care sections of nursing homes. Knowing what matters to residents is likely to expand on current ways to care for residents and to add value to assessments used for improving quality of care in

nursing homes. Integrating things that matter to residents in their care may optimize residents' right to self-determination because they will make known things that are most important to them while living in nursing homes. In addition, the study findings may reveal things that do not matter for residents in nursing homes that may offer caregivers new insight about what quality care is for residents. Assuring that nursing education includes a focus on what residents determine for themselves matter most to them in nursing homes may assist nursing educators to review and improve their curricula to better prepare nurses for geriatric/gerontologic care in nursing homes.

Aims

Specific Aim 1. Describe things that matter to residents while living in nursing homes.

1.1 What are things that matter in the words of the residents?

1.2 What makes these things matter to residents?

1.3 What things that matter to residents in nursing homes may be included in their care?

1.4 Are things that matter to residents captured in current person-centered care practices in nursing homes?

Conceptual Definitions

Nursing Homes

Nursing homes are private or public facilities providing nursing and rehabilitative services for persons who need long- or short-term care (USDHHS CMS, 2013c). Nursing homes provide a living location with a social structure in addition to health care for residents (IOM, 1986). Persons are admitted to nursing homes if their health needs are

beyond what can be met at home (USDHHS National Institute on Aging, 2010). Licensed staff members including registered nurses (RNs) and licensed practical nurses (LPNs) render some care. Other staff members such as certified nursing assistants (CNAs), social services workers, physical and occupational therapists, and dieticians also provide services. In the United States, 63% of nursing home facilities are privately owned and for-profit. The remaining nursing homes are privately owned and not-for-profit or are owned by governmental agencies. More than 60% of nursing homes have 100 beds or more (USDHHS CMS, 2010). Three privately owned, for-profit nursing homes with 100 beds or more located in the Midwestern United States were selected for interviewing residents for this study.

Long-term Care in the Nursing Home

Individuals who reside in nursing homes for longer than 100 days are considered to be receiving long-term care (USDHHS CMS, 2014b). Long-term care in nursing homes differs from skilled care, also referred to as short-term care, where residents receive rehabilitative or skilled nursing and plan to be discharged to home. Short-term care services typically are covered by Medicare for the first 100 days of skilled care (USDHHS CMS, 2014b). This study targeted residents who receive long-term care in nursing homes.

Residents

Residents are persons who reside in nursing homes for long-term or short-term care. Residents have care needs that vary from limited assistance to needing total assistance with their daily activities (IOM, 1986). Five residents who live in nursing

homes with the intention of staying more than 100 days were invited to participate in this study.

Nursing Home Quality of Care

Quality in nursing homes reflects services that are provided with respect and choices for residents in addition to clinical outcomes that are based on evidence-based practice (Advancing Excellence in American's Nursing Homes Campaign, 2012). The Advancing Excellence in America's Nursing Homes Campaign is an ongoing movement that was launched in 2006 by groups of healthcare professionals, governmental agencies, researchers, and academicians who are interested in nursing home quality (Advancing Excellence in America's Nursing Homes, n.d., "Purpose and Description"). The campaign, comprised of consumers, caregivers, healthcare professionals, and governmental agency representatives, encourages nursing home staff and consumers to participate in monitoring and promoting excellent care in nursing homes. The USHDDS CMS (2010) established a goal for nursing homes to include residents' preferences, in addition to their physical and clinical conditions, in their nursing home quality measures. Strategies for improving quality of care in nursing homes should reveal residents' concerns about quality of care with nursing home staff according to the CMS. To promote the public's education about nursing home care, The Nursing Home Quality Initiatives, founded by the USDHHS in 2002, established measures that guide nursing homes' clinical care performances such as administering immunizations and preventing infections, pressure sores, weight loss, and immobility.

Structure, process, and outcomes are dimensions used by healthcare organizations to evaluate quality of care (Donabedian, 1966). The literature about quality of care in

nursing homes typically reveals comparisons of quality measures in these dimensions (National Research Council, 2001; Rantz et al., 1999; Ryden et al., 2000; USDHHS CMS, 2012b). Structure reflects the settings and instruments used to achieve the product of care such as staff training, insurers and payers for services, and facility characteristics (Donabedian, 1966; National Research Council, 2001). Process reveals how caregivers render care including the appropriateness and proficiency of services provided for patients (Donabedian, 1966; National Research Council, 2001). Process variables for residents in nursing homes reflect how healthcare givers render care for treating pain, pressure ulcers, nutritional status, depression, and other clinical conditions (National Research Council, 2001). Outcomes provide measures of achievements or goals for improving the health statuses of patients and relay information about the effectiveness of care processes for patients (Peters, 1995).

Person-centered Care

Talerico, O'Brien, and Swafford (2003) described person-centered care as care rendered by caregivers who respect residents' values, preferences, and needs. Elements of fostering consistent and trusting relationships, emphasizing freedom of choice, promoting individually defined risk-taking, and respecting the uniqueness of residents are elements reflected in person-centered care in nursing homes.

Residents' Satisfaction

Resident satisfaction is derived from patient satisfaction, described as the patient's view of quality of care received (Ryden et al., 2000). Satisfaction or dissatisfaction occurs when the care performed by the provider confirms or disconfirms the patient's expectation of care (Smith, 2000). Respect for the patient's values,

preferences, and needs; information; physical comfort; emotional support and alleviation of fear or anxiety; involvement with friends; specific care providers; and environment were found to be predictors of satisfaction for residents in nursing homes (Ryden et al., 2000).

Things that Matter

Buhler (1977) described things that matter to a person as things that the person perceives as more important than other things. Things that are more important to a person reveal “what a person is about” (Buhler, 1977, p. 20). Persons search for things that matter to them in a persistent or on an intermittent manner according to their goals. These goals provide a sense of direction for what the person feels obligated to do. The goals may be constructive and sensible or may be destructive and insensible. These things that matter to the person provide direction to the person’s expectations or aspirations. Persons who experience nothing that matters to them feel a sense of “floundering” due to a lack of possessing goals or direction in what they desire or what they want to accomplish (Buhler, 1977, p. 20). Buhler (1964) asserted that an older person tends to enter a “retirement pattern” or a “fulfillment pattern” (p. 5). An older person entering a retirement pattern finds retirement to be a fulfilling closure in life. On the other hand, an older person in the “fulfillment pattern may continue to seek fulfillment through additional duties or tasks in the way of social status or work” (Buhler, 1964, p. 5). In general, regardless of a person’s accomplishments in attaining goals in life, the person has purposes or intentions that reveal some type of a goal-pattern (Buhler, 1964).

Buhler (1968) described four tendencies that a person utilizes when attaining fulfillment in life: need satisfaction, self-limiting adaptation, creative expansion, and

upholding of the internal order. Need satisfaction reflects having pleasurable things in life including giving and receiving love. Self-limiting adaptation reveals the ability to accept limitations and adapting to hurtful events in life. Creative expansion reveals an ability to accomplish life events according to the person's desires. Upholding the internal order reveals the person's beliefs, feelings of worth and success, and the ability to place others above oneself (Buhler, 1964). The person manages need satisfaction and internal order for gaining stability and self-limiting adaptation and creative expansion to manage changes in life. Maintaining life fulfillment occurs when the person is successful in restoring deficiencies that occur in life and can continue to uphold the internal order (Buhler, 1968).

Carlsen (1991) targeted her discussion about things that matter specifically on older persons. Things that matter are the "meaning-makings" or things that promote a sense of order and significance for older persons (Carlsen, 1991, p. 155). Experiences that bring personal meaning are derived from one's values, purpose, and reality of the world. Excitement, passion, loss, and grief occur when a person's emotions and meaning-makings become entwined. Thus, it is essential that healthcare team members make sure to understand the older person's emotional life during care.

Qualitative Description

Maxwell described a "reflexive process" where researchers may need to modify the research design during any stage of the research process when conducting qualitative research (2005, p. 2). Researchers performing qualitative studies seek for understanding about how processes lead to outcomes instead of directly searching for outcomes or causal explanations (Maxwell, 2005). When using qualitative description, researchers are

inclined to draw from the ideas of naturalistic inquiry where they study something in a natural or normal state (Sandelowski, 2000). Interview data is taken as something actually described by the participant. In other words, the researcher takes the data for “what it is” when using a qualitative method (Sandelowski, 2010b). It is critical to move the data toward an idea or a concept that promotes new insight. The qualitative researcher should be sensitive to theory, yet permit the data to naturally unfold.

Summary

Although strategies used in person-centered care and satisfaction surveys have been found to improve quality of care in nursing homes, it is unclear that these strategies include things that matter to residents who live in nursing homes. Rendering and assessing care that embraces what residents state matters is consonant with assuring that care reflects the uniqueness of residents. This research study provided an opportunity to interview residents who agreed to share things that matter to them while living in long-term care sections of nursing homes. The results of this study will add new knowledge for (a) understanding things that matter from residents’ perspectives, (b) enhancing care that incorporates things that residents describe as mattering to them, (c) expanding the state of the science of person-centered care, (d) improving assessments of quality of care in nursing homes, and (e) advancing gerontological nursing education.

CHAPTER TWO. REVIEW OF THE LITERATURE

There is a paucity of literature about what residents describe for themselves that matter to them while living in nursing homes. A review of the literature that included person-centered care and satisfaction surveys found these two concepts as the current major attempts used to capture what is important to residents for improving quality of care in nursing homes. The literature revealed that great strides have occurred in making known the need to implement person-centered care and assessing residents' satisfaction in nursing homes during the last decade. However, there is a lack of clarity about things that residents self-report matter to them during their residency in the long-term care section of nursing homes. Additional research is necessary for capturing things residents describe matter to them that may expand on person-centered care strategies and ways of assessing residents' satisfaction in nursing homes.

Recognizing a Concern about Nursing Home Care

My research journey began with an interest in seeking ways to improve care of residents in nursing homes. My initial research question to address quality of care—"What do residents consider as quality nursing care in nursing homes?"—arose from my experience as a former director of nursing in a nursing home. During my work in the nursing home, I continually strived to advance teamwork efforts with staff members for improving nursing care for residents. I found that staff members in nursing homes demonstrated unique ways of expressing commitment and respect for residents. I found it interesting that staff members demonstrated loyalty in special ways with residents, yet occasionally treated residents with less than desired professionalism in their manners of speaking and behaviors. Perhaps nursing staff members develop a level of

comfort that exceeds the boundaries of professionalism because of their getting to know the residents on a daily basis.

After many years of working as a nurse in acute care settings, I soon realized that nursing home staff members earn less compensation than nursing staff members in acute care environments. Nonetheless, it was admirable to see these staff members demonstrate genuine compassion for the residents. It was common for the staff members to use their own money to purchase special gifts such as clothing, lotions, stuffed animals, and bathing products for residents; to come into the nursing home to be with residents who were in the dying process; and to take residents out of the nursing home on special trips that were important to residents. I will never forget the time that two CNAs took a resident out “on the town” one Saturday evening. The attorney-in-fact for the resident was concerned about the CNAs returning with the resident to the nursing home so late at night. The resident stated,

Please see that the CNAs do not get into trouble. I had the best time of my life Saturday night!!! They took me out to dinner, then shopping and bought me new tennis shoes. See I have them on, and we drove around town the rest of the night. I had the best time I have ever had!

It was common for the nursing staff members to demonstrate social behaviors that violated professionalism as I had become accustomed to in the acute care environment. I witnessed nursing home caregivers make choices for residents, respond to residents with comments that were inappropriate during care, and overall demonstrate a lax attitude at times during care. I often wondered how I would perceive this care if I lived in the nursing home. At the same time, I never doubted that most of the nursing caregivers intended to render care with empathy and compassion for the residents in ways that I predicted they would care for their own family members. I often contemplated about

ways the nursing profession could assist nursing home staff members to continue rendering care with special compassion that was characteristic of these staff members, yet gain understanding about the level of professionalism in care that nursing home residents so much deserve to receive.

Building on my interest for improving nursing home care, I anticipated that a quantitative approach for measuring objective data targeting variables of empathy, reliability, and consistency would be a good fit for my study. I studied ways that resident and caregiver relationships may enhance resident well-being and resident care outcomes building on the work of Winnicott (1970), McGilton (2002), and McGilton, Pringle, O'Brien, Wynn, and Steiner (2005). During my beginning research work, I developed the following conceptual framework to guide my study (see Figure 1).

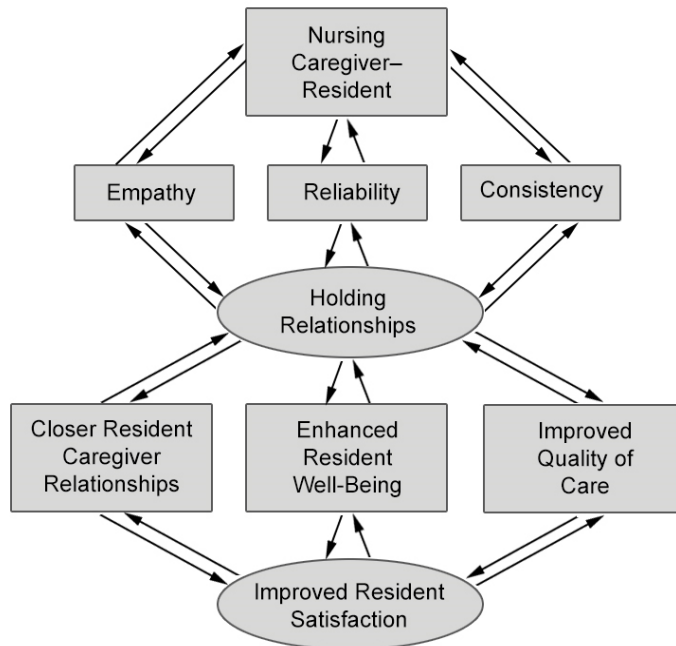


Figure 1. The Conceptual Model of Care in Therapeutic Relationships and Resident Outcomes is derived from the Model of Care proposed by McGilton (2002) to determine outcomes of empathy, reliability, and consistency in correlation with resident-caregiver relationships, enhanced well-being, and improved resident satisfaction.

The Relational Care Scale (McGilton et al., 2005) that I planned to enhance for my study included participant Likert scale questions measured from 1 (*Never*) to 5 (*Always*). As I continued studying this instrument, two questions surfaced for me:

- What if empathy, reliability, and consistency were not reflective of quality of care from the residents' perspectives?
- What if residents experienced quality of care as something entirely different than empathy, reliability, or consistency?

It became clear to me that the approach that I was considering might not be the best method to learn what quality of care is from residents' perspectives. My goal was to understand what quality of care meant from residents' perspectives. I was not sure at that point if empathy, reliability, and consistency would provide knowledge about residents' own ideas about care.

I refocused my research using an interpretive phenomenology methodology where I planned to interview residents to search for meaning about quality of care from residents' perspectives as they lived in nursing homes. I continued to study qualitative research and joined an interpretive phenomenology group where expert faculty led students in learning more about developing qualitative research questions and analyzing data. I conducted a pilot study asking residents about their experiences of quality of care in nursing homes. The residents' responses reflected broad perspectives of living in nursing homes. The residents seemed interested in sharing stories about overall important things to them while living in nursing homes.

Because the residents in the pilot study seemed more focused on a broad perspective of living in nursing homes rather than quality of care, I again refocused the

study on a qualitative description methodology that would direct me in an interpretive method with less inference using the concept of meaning for residents in nursing homes. I found the meaning concepts to include meaning in life, personal meaning, and meaning-making. These abstract concepts reflected unclear definitions that became cumbersome as I attempted to apply them to what residents might perceive as meaningful in nursing home care.

The concept of things that matter evolved from the meaning-making literature that specifically targeted older persons (Carlsen, 1988, 1991). Things that matter identify what persons pursue as more important over other things (Buhler, 1977) and seemed to fit my study for understanding what was most important to residents while they live in nursing homes (see Figure 2).

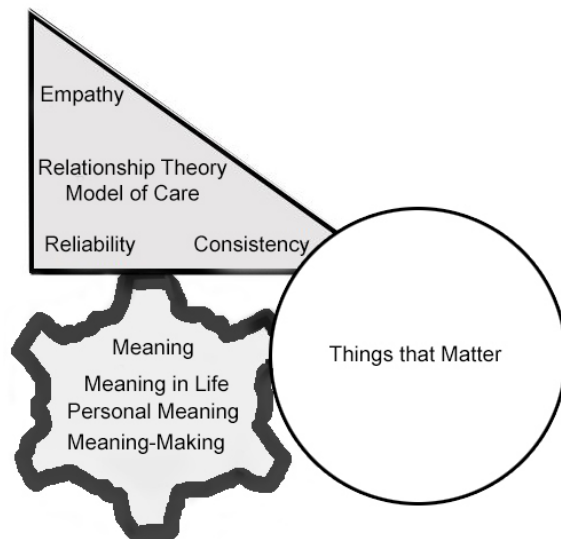


Figure 2. Illustration of evolving research topic: Things that matter to residents while living in nursing homes.

The research focus on things that matter to residents while living in nursing homes originated with a linear method of measuring empathy, reliability, and consistency. Further study led to a non-linear approach that focused on the many

concepts of meaning. A circular process used to learn about things that matter to residents evolved from the research on meaning-making.

Care in Nursing Homes

Efforts to improve nursing home care emanated from the focus on regulatory reform after the IOM's enacted recommendations in the Omnibus Budget Reconciliation Act (OBRA) of 1987 for improving quality of care in nursing homes (IOM, 2001b). Because of the IOM's recommendations, clinical outcomes improved in nursing homes (IOM, 2001b) and state surveys have continued to reveal a decline in cited deficiencies revealing actual harm (USDHHS CMS, 2012a). Although it has been over 20 years since the OBRA 1987 enactment for improving quality, ongoing concerns about care in nursing homes continue to exist (Commonwealth Fund, 2014; Doty et al., 2008; Koren, 2010; Levenson, 2009; Ragsdale & McDougall, 2008; USGAO, 2009; Wiener et al., 2007). Because of the unending concern about delivery of care in nursing homes, in 2007 another committee formed within the IOM whose goal was to suggest methods for including older persons as partners with healthcare givers in planning care. The committee targeted suggestions about retaining and increasing the number of caregivers and enhancing caregivers' competence of caring for elderly persons to assure high-quality care (IOM, 2008).

Even though criticisms of care in nursing homes are apparent in the literature, nursing homes have received insufficient recognition for positive changes that have occurred in care (Levenson, 2009). Strategies to improve care using an approach of changing the institutionalized culture to a home-like environment that promotes person-centered care continue to increase as the center of attention in nursing home

literature. Governmental agencies and national associations have established initiatives to improve nursing home quality by implementing person-centered care where residents' individual values and needs are intended to be central in their nursing home care. Most notably, the CMS in collaboration with the Pioneer Network, an association of advocates who seek to improve quality of the nursing home culture, has taken major steps to facilitate efforts for promoting person-centered care in nursing homes. The goal of CMS and Pioneer Network is to transform the nursing home culture from an institutional environment to a home-like environment while ensuring that residents are provided choices and encouraged to maximize independence in ways that are meaningful in their daily lives (Pioneer Network, 2010). The mission of the Advancing Excellence in America's Nursing Homes Campaign is to assist nursing homes in implementing individualized care and achieving excellence in quality of care (Advancing Excellence in America's Nursing Homes, n.d., "Purpose and Description"). The campaign targets process goals of "improving stability, increasing use of consistent assignment, increasing person-centered care planning and decision-making, and safely reducing hospitalizations" in addition to clinical goals of "using medications appropriately, increasing resident mobility, preventing and managing infections safely, reducing the prevalence of pressure ulcers, decreasing pain symptoms" (Advancing Excellence in America's Nursing Homes Campaign, 2013, para. 5).

A shift in focus from nursing care task-oriented measures to giving residents voice about their preferences is finally occurring. Governmental regulatory agencies, healthcare organizations, and the overall population are becoming increasingly aware that the meaning of quality of care in nursing homes should represent more than assessments

of outcomes that commonly reflect measurements of residents' clinical health statuses such as immunizations, pressure ulcers, weight loss, and immobility (USDHHS CMS, 2014a). In recognition of that awareness, the CMS acknowledged that the time has come when caregivers should ask residents about their preferences and revise the routine resident clinical assessment, the Minimum Data Set (MDS), used to assess all residents in Medicare- and Medicaid-reimbursed nursing homes (USHDDS CMS, 2010). The MDS now targets the resident as the primary source of information and includes open-ended questions; however, the MDS continues to provide the direction in content of questions within the sections where residents are encouraged to share their voice during the assessment (Saliba & Buchanan, 2008). Another advancement of the MDS to target care that is important to residents includes algorithms and color codes cued as the result of residents' identification of items that are missing during their care. Staff members are instructed to target the color-coded indicators as priority areas during care (Degenholtz, 2013).

Studies have shown that changes from the traditional model of nursing home to more home-like environments support a change in culture that improves quality of life for residents. The Green House program uses the concept of small-housing units with a consistent caregiver, called *Shahbaz*, who cooks, cleans, and provides resident care (M. Villarreal, personal communication, August 11, 2010). Kane, Lum, Cutler, Degenholtz, and Yu (2007) found that residents experienced improved quality of life when receiving care in Green Houses. Implementation of another program, the Eden Alternative (Robinson & Rosher, 2006), focuses on shared decision-making and minimizing hierarchies of care in addition to providing children, plants, and animals to

alleviate residents' boredom. Integration of the Eden Alternative also saw the benefit of decreased staff turnover and increased occupancy of beds (Robinson & Rosher, 2006).

The various scopes of actual changes in nursing home cultures including the achievement of creating home-like environments and including residents in care (Rahman & Schnelle, 2008) change the nursing home culture, which should respond to residents' preferences (Burger et al., 2009). Even though nursing homes continue to improve care, directly involving the residents in culture reform that has revealed improved care has been neglected (Shura, Siders, & Dannefer, 2010). It is possible that adoption of person-centered care strategies derive from staff members' perceptions of care versus the residents' perceptions of care. Carlsen (1991) claimed that permitting residents to share stories about things that matter to them provides an opportunity for residents to gain new understanding and creative expression in their lives that are essential in creative aging. Creative aging is aging that is positive with lifelong development and occurs when individuals face their mortality "considering the worst and exploring the best" (Carlsen, 1991, p. ix). Learning about things that residents share which matter to them during nursing home care may enhance understanding about person-centered care practice that promotes creative aging.

Person-Centered Care

There is a plethora of literature about person-centered care strategies used in overall healthcare organizations. Person-centered care is the term used for centering care on residents in nursing homes and has been claimed to go beyond the concept of patient-centered care to emphasize an individual's needs as defined by the individual (Talerico et al., 2003). In order to understand the development of person-centered care

and because patient-centered care is an overarching term for care of patients in all types of healthcare organizations, the concepts of patient-centered care and person-centered care were explored.

The concept of patient-centered care extends from the notion of client-centered therapy recognized in the work Carl Rogers in the 1940s–1950s. Rogers' approach to client-centered therapy concentrated on perceiving the client's world as the client perceived the world (Rogers, 1949). Positive regard was a compelling factor in forming positive relationships according to Rogers (1959). Positive regard occurs when a person receives positive attitudes from others. A person experiencing positive regard from others will attain an increased positive attitude of self and condition of worth. Conditions that are necessary to improve relationships and psychological adjustments for clients consist of establishing congruency in experience, awareness, and communication between the therapist and the client according to Rogers (1949).

The literature on patient-centered care has grown considerably in application to healthcare environments since the work of Rogers. With the continued focus on quality of healthcare, it is not surprising that the idea of patient-centered care should become a dimension of quality as described by Berwick (2009). Organizations should be certain that the actual performance of patient-centered care reflects quality instead of solely measures of patients' health statuses and outcomes (Berwick, 2009). Patient-centered care is embedded within the IOM's six aims to improve quality of care within the next decade reflecting care that is safe, effective, patient-centered, timely, efficient, and equitable. The IOM also expressed concerns about the care of the older population, which is predicted to double by 2030. The IOM established a goal for health caregivers to place

focus of care on the patient and family in the redesign for overall health care to meet the needs of persons over the age of 65 (IOM, 2008). Although there are various components of patient-centered care described in the literature, Lutz and Bowers (2000) asserted that one common element found within all of the different concepts of patient-centered care is the goal to meet patients' needs from patients' perspectives (See Table 1).

Table 1

Elements of Patient-Centered Care

Author	Patient Centered Care
Aragon (2003)	Patients make the judgment about quality of services. Primary providers' deliver a highest clinical utility of care for patients and focus on patient satisfaction that is reliant on a patient-centered care approach.
Berwick (2009)	Implement patient-centered care as a quality dimension. Place patients and families in control decisions. Extend transparency in all care practices. Adapt to individualization of patients. Train students and professionals in emotional intelligence, mindfulness, inquiry, and dialogue. Modernize healthcare systems so that they invite and adopt patient-centered care practices.
Gerteis, Edgman-Levitan, Daley, & Delbanco (1993)	Respect patients' expressed values, preferences, needs. Deliver care with consistency and effective communication. Provide information, communication, and education. Promote physical comfort. Provide emotional support and minimize fear and anxiety. Promote family and friends involvement. Provide elements for health transition, continuity of care, and support.
Ingersoll et al. (2002)	Decentralize services and perform care to groups of patients with similar needs. Bring service to patient's bedside.

Table continues

IOM (2001b)	Honor patients' choices. Patients are active in decision-making about care. Implement a culture and social context with respect for patients.
Quality & Safety Education for Nurses (QSEN; 2007)	Patients are partners in care and designated in control of care. Respect for patients' values, preferences, and needs.

Talerico et al. (2003) emphasized the importance of differentiating between patient-centered care and person-centered care when describing care for residents in nursing homes. Person-centered care provides direction for caregivers to recognize and embrace the uniqueness of each person whereas patient-centered care typically has been associated with hospital design or staffing models created to modify care to meet patients' needs, values, and preferences (Talerico et al., 2003). Because residents' care is typically long-term, characteristics in nursing home care is different from in hospital care. Expected outcomes of residents' health statuses and the fact that the nursing home may become the person's actual home are key factors to consider in person-centered care strategies. Elements of person-centered care described in the literature are included in Table 2.

Table 2

Elements of Person-Centered Care

Author	Person-centered Care
Crandall et al. (2007)	Know the person. Maximize the provision of autonomy and choice. Perform quality care. Provide nurturing relationships. Provide a supportive physical and organizational environment.

Table continues

Flesner & Rantz (2004)	Change the philosophy from care and protection of the body to support of residents' personal satisfaction. Create individualized living spaces. Empower staff as individual resident advocates. Respect residents' unique life patterns, preferences, and individual needs. Promote residents' personal growth, development, sense of contribution, and connection to the community.
Jones (2011)	The resident makes decisions such as what time to wake up, go to bed, have meals, and bathe. Care is centered on the relationship of the residents and primary staff members using the Holistic Approach to Transformational Change (HATCh) Model. The model emphasizes providing activities and practices in a home-like environment where overall care is led by staff members providing direct care. Relationships among staff members, family, and community are encouraged. Governmental regulations supporting transformation from the traditional nursing home environment to a home-like person-centered care environment are integrated in the model.
Koren (2010)	Individualize care by honoring residents' rights and including residents' input in care. Focus on culture with decentralizing departmental hierarchy.
McCormack & McCrance (2010)	Pre-requisites of nurse attributes, therapeutic relationships, caring environment, and person-centered outcomes reveal relationships of person-centered care.
Pioneer Network (2009)	Care is organized to accommodate residents' preferences. Residents make decisions about their routines. Staff members honor residents' lifelong preferences and understand residents' quality of life priorities and goals of care.
Talerico et al. (2003)	Know the persons and respond to their individual and family characteristics. Provide meaningful care with respect to the persons' values, preferences, and needs. View persons as bio-psychosocial human beings. Foster consistent and trusting relationships. Emphasize freedom of choice and encourage individually defined risk-taking. Promote physical/emotional comfort. Involve patients' family, friends, and social network.

Table continues

Tellis-Nayak (2007)

Initiate a goal of meeting the residents' well-being. Engage staff in person-centered work environment. Promote caring culture for staff and residents. Affirm residents' dignity, respect residents' choices and assist them in maximizing their own choices, and empower them.

As Nolan, Davies, Brown, Keady, and Nolan (2004) projected, concepts of person-centered care have become a focus of quality thus far in the twenty-first century. In parallel with person-centered care, descriptions of client-centered and patient-centered care are emerging in the literature on quality of care in nursing homes (Nolan et al., 2004). Descriptions of person-centered care as shown in Table 2 support Nolan's assertion that residents and relationships are central in the focus of person-centered care versus regulations, policies, and procedures that are typically targeted in practice of care that is not person-centered.

The concepts of relationships and engagement between residents and staff members commonly surfaced in the person-centered literature. Nolan et al. (2004) suggested expanding beyond person-centered care concepts of knowing residents and individualizing their care. Developing relationships during residents' care ideally embraced a six-senses framework for residents that included: security, belonging, continuity, purpose, achievement, and significance during care. When staff members developed relationships that captured the six senses, both residents and staff members were enriched promoting feelings among residents that they "matter" (Nolan et al., 2004, p. 52). In addition, students who were included in the resident and staff relationships that embraced the six senses reported having enriched and positive clinical experiences according to Nolan et al. (2004).

The relationship between residents and primary staff members is the “heart of person-centered care” (Jones, 2011, p. 18). Consistency in staff members’ assignments and getting to know the residents add to the development of the resident and staff relationships. Because of the lack of research on care-providers and residents’ relationships, McGilton and Boscart (2007) interviewed staff members, residents, and family members. The residents felt they had a close relationship with a care provider when they believed the care provider was a confidant with them, had the residents’ best interest at heart, took initiative by doing extra tasks without the residents asking them, and was there for them when they needed. In addition, Castle, Ferguson, and Hughes (2009) described humanistic caring based on positive relationships that foster empathy and compassion during care.

Flesner (2003) included a model of person-centered care that targeted relationships between staff members and residents. The person-centered care delivery model was implemented in a nursing home where residents and staff members were interviewed. The residents’ interviews revealed the following themes: (a) employees were like family who provided the residents with control of their schedules of care; (b) family members felt confident that the residents were treated appropriately and the residents’ illnesses were managed so that the residents could optimally partake in activities; (c) the residents found trips to events meaningful to them; (c) food offered around the clock was appreciated; and (d) the residents desired to take part in the activities in the nursing homes.

McCormack and McCrance (2010) also included a focus on relationships in their person-centered care model. The person-centred nursing framework is an example of a

model developed for overall nursing care and person-centeredness. Having a value of respect for persons, providing rights to their self-determination, and having mutual respect and understanding should be supported by empowerment within the culture. The model includes four constructs: (a) pre-requisites that reveal professional nurse competence including nurses' awareness of their own beliefs and values; (b) the care environment that reflects skill, shared decision-making, relationships of staff, sharing of power, and staff members' willingness to take risks for performing optimal care; (c) person-centered process that discloses nurses' ability to engage with patients using presence and sympathy; and (d) outcomes of the results of person-centered care reflected by patients' satisfaction of care, establishing well-being, and therapeutic environment (see Figure 3).

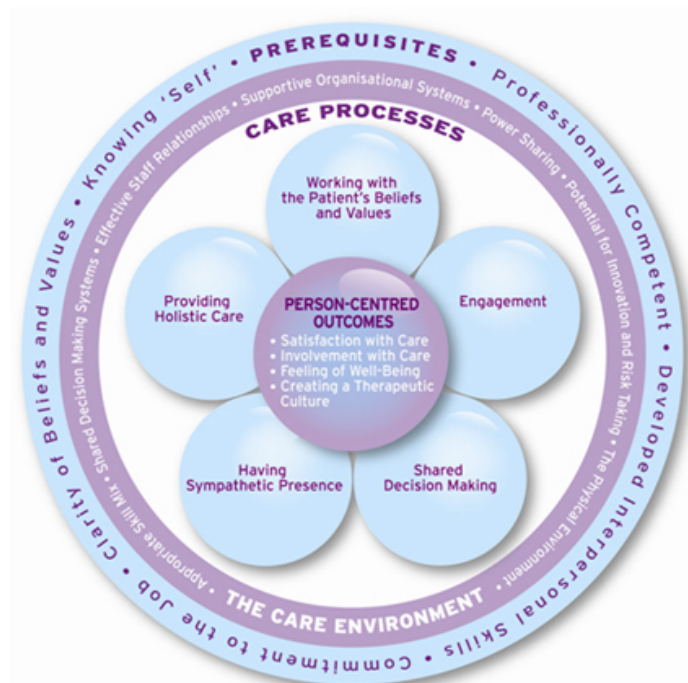


Figure 3. Characteristics of residents participating in study of are depicted through the interrelationships across the four constructs of the person-centered nursing framework focus on the person: (a) Prerequisites reflect a nurse's attributes as a professional; (b) The care environment reveals the context of care delivery; (c) The person-centered process

focuses on therapeutic relationships; and (d) Outcomes centered in the model reflect person-centered nursing care by B. McCormack and T. McCrance, 2010, *Person-centred nursing theory and practice*, p. 95. Copyright 2013 by B. McCormack (see Appendix A). Used with permission.

The person-centred nursing framework is considered a middle-range theory with focus on specific concepts described within the four constructs. Although the framework is relatively new, it is commonly discussed in the person-centered care literature specific to care of residents in nursing homes (Edvardsson, Fetherstonhaugh, & Nay, 2011; Edvardsson, Varrailhon, & Edvardsson, 2013; McCormack, Dewing et al., 2010; McCormack, Roberts, Meyer, Morgan, & Boscart, 2012; McGilton et al., 2012; Medvene & Lann-Wolcott, 2010; Rosvik, Kirkevold, Engedal, Brooker, & Kirkevold, 2011; Sjogren, Lindkvist, Sandman, Zingmark, & Edvardsson, 2012).

Further descriptions of person-centered care were focused on care in hospitals or acute care settings (Clarke, Hanson, & Ross, 2003; McCormack, Karlsson, Dewing, & Lerdal, 2010; Ursel & Aquino-Russell, 2010). In addition, models of person-centeredness specific to residents with dementia were described in the literature (Burack, Weiner, Reinhardt, Annunziato, 2012; Buron, 2008; Edvardsson & BA Hons, 2010; Kitwood, 1997; Seifert, Flaherty, & Trill, 2013). These studies revealed staff members using a combination of person-centered and dementia-specific care methods that are holistic and focus on the person interactively.

Other terms such as person-directed care and resident-directed care were found in the literature. Person-directed care denotes persons guiding their own care based on a person-centered care philosophy (White, Newton-Curtis, & Lyons, 2008). Residents have direction in establishing goals during person-directed care (National Consumer Voice for Quality Long-Term Care, 2009). It is essential for nursing home staff members to find

ways to sustain person-centered care so they can overcome the tendency to rely on traditional ways of performing care (J. Heid-Grubman, R. Priest, C. Ende, D. Hyde [Presenters], live webinar, October 23, 2012). Resident-directed care is care guided by the resident. Examples of resident-directed care include residents' choice of their bed times and methods of dining and bathing. Encouraging residents to partake in learning circles and resident councils where they share feedback are methods used during resident-directed care (White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009). Encouraging residents to make decisions, getting to know residents as individual persons, and placing residents ahead of care tasks are examples of resident-centered care (Robinson & Rosher, 2006).

The interchangeable use of terms such as person-directed, resident-directed, patient-centered, and person-centered that exist in the literature has contributed to lack of clarity for understanding person-centered care (Fazio, 2008; McCormack, Karlsson et al., 2010). McCormack et al. (2012) compared models of culture change, person-centered care, and relationship-centered care, and found gaps in the comparisons of the models. The literature overall tended to focus on the exclusiveness of the models rather than the complementary aspects although there were overlaps of concepts. It is important to use clear theoretical and philosophical foundations in order to promote accurate development of person-centered care models and frameworks (McCormack, Karlsson et al., 2010; McCormack et al., 2012). Because of the lack of empirical evidence to support an operational framework for person-centered care, further study is needed to develop strategies for implementing and evaluating person-centered care (McCormack, Karlsson et al., 2010).

Various philosophical views and models of person-centered care surfaced in the literature including the person-centred nursing framework described by McCormack and McCrance (2010). Because the philosophy of person-centered care described by McCormack and McCrance targeted specific components of nursing care that included engagement, shared decision-making, sympathetic presence, holistic care, and acknowledgement of patients' beliefs and values; it was considered suitable for describing person-centered care in this study. The term *sympathetic* was used in the model because it reveals a "quality of being affected" that occurs with feelings versus *empathetic presence* that means presence with projecting personality into a situation for gaining understanding (McCormack & McCrance, 2010, p. 239).

The literature reveals that nursing home caregivers attempt to embrace what matters to residents by capturing preferences, offering choices, providing meaningful care, recognizing individual needs, respecting autonomy, soliciting expression of needs, and providing a caring culture that promotes dignity, respect, contribution, and empowerment as indicated in Table 2. However, the following major question needs to be addressed: Are things that matter to residents captured in current person-centered care practices in nursing homes?

It seems that capturing preferences, offering choices, providing meaningful care, recognizing individual needs, respecting autonomy, soliciting expression of needs, and providing a caring culture that promotes dignity would be included in care that reflects things that matter to residents. Knowing what things matter to residents in nursing homes may actually occur if the preferences and choices are designated by the residents themselves and the individual needs that are met are truly the residents' needs. However,

clarity is lacking in the literature about ways residents express their needs and how residents make choices in nursing homes. Residents lack autonomy in making their own decisions based on their own needs and desires in nursing homes (Kane & West, 2005; Persson & Wasterfors, 2009). In addition, only a few nursing homes are successfully changing their culture by operationalizing person-centered care (Crandall et al., 2007; Koren, 2010; Rahman & Schnelle, 2008). Nursing care directed by things that matter to residents may advance ways to operationalize person-centered care and lead society to change the perspective that residents lack autonomy in decision-making.

The idea of integrating person-centered care in nursing homes is not new. A conception of changing the culture in nursing homes began in the 1970s when a consumer advocacy group, the National Citizens' Coalition for Nursing Home Reform, shared its concerns about the lack of standards of care in nursing homes. The coalition was comprised of citizen and ombudsman groups who launched campaigns about quality of care that included giving the residents a voice in their care. Over the past 30 years, this advocacy group, now titled the National Consumer Voice for Quality Long-Term Care, has provided leadership for regulatory and legislative policy developments for improving quality of care that instills giving residents a voice in their care (National Consumer Voice for Quality Long-Term Care, n.d., "Consumer Voice").

Person-centered Care in the Move to Change Nursing Home Culture

There is a vast amount of literature about person-centered care being a key component in the culture change movement in nursing homes (Crandall et al., 2007; Flesner, 2009; Pioneer Network, 2010; Stone, Bryant, & Barbarotta, 2009; Talerico et al., 2003). Culture change was defined by representatives of the Pioneer Network as the

transformation of care based on values and practices that are directed by older adults in nursing homes (Pioneer Network, 2010). Representatives of the National Consumer Voice for Quality of Long-Term Care (n.d., “About consumer voice”) described culture change as a change in philosophy to de-institutionalize care using a resident-directed approach. Residents directing their care in person-centered environments reveal staff members’ providing residents with “choice” and the opportunity to “practice self-determination in meaningful ways” (Kantor, 2010, para. 2). The Pioneer Network’s efforts to lead the culture change movement began in 1997 with the aim to encourage nursing homes to practice patient-centered care (Flesner, 2009; Pioneer Network, 2010). The culture change movement continues to evolve with a goal of transforming nursing homes from institutions to person-centered care homes that reflect the following: resident direction in personal care; a homelike atmosphere that is less institutional; close relationships between residents, family, staff, and the outside community; staff empowerment when responding to residents’ needs and desires; collaborative decision-making with a decreased hierarchical structure; and continual quality improvement processes with valid measurements (Koren, 2010).

The shift of regulations to focus on initiatives that encourage culture change are finally emerging although there is much work to be accomplished (Stone et al., 2009). Federal regulations have supported the drive toward person-centered care in changing the nursing home culture as well. The “Residents’ Bill of Rights,” developed to assure residents’ dignity, autonomy, and provision of choices, was included in federal regulations in 2000. In addition, federal regulations mandate quality-of-life requirements for providing an environment that reflects individualized care for residents in nursing

homes (Flesner, 2009; Requirements for States and Long Term Care Facilities of 1989; USDHHS CMS, 2010).

Ongoing work by the CMS includes the “Nursing Home Action Plan” for advancing nursing home quality (USDHHS CMS, 2012). The action plan aims to improve the experience of care and health of populations and to reduce the cost of care for residents in nursing homes. The first objective in the action plan is to enhance consumer engagement by promoting consumers to manage their own care. In addition, the action plan has joined initiatives to advance culture change in nursing homes (USDHHS CMS, 2012a).

Education and training are strategies used to integrate person-centered care in nursing homes (Kemeny, Boettcher, DeShon, & Stevens, 2006). Yeatts and Cready (2007) found that work teams promoted empowerment for CNAs, the frontline caregivers of residents, and led to increased empowerment and “buy-in” for implementing person-centered care.

In order to implement person-centered care, practitioners need to understand clients’ personal meanings and values (Clarke et al., 2003). Clarke et al. (2003) performed a study of older persons in hospitals and nursing homes and found that story-telling facilitated nurses and support staff in seeing the patient or resident as a person. Story-telling revealed the patients’ and residents’ personal attitudes, experiences, and personal meanings for the hospital and nursing home staff. Parallel with the idea that staff members need to see the resident as a person during person-centered care, Leutz, Bishop, and Dodson (2009) identified the impact of frontline workers developing knowledge about residents’ needs and preferences. Leutz et al. discovered themes of

partnership in conferences with other nursing homes and expert-led training programs as successful in facilitating person-centered care in two nursing homes.

Principles and practice of person-centeredness that embrace individual growth and foster well-being should replace traditional policies and procedures commonly used to assess organizational accountability (J. Heid-Grubman, R. Priest, C. Ende, D. Hyde [Presenters], live webinar, October 23, 2012). Ende iterated that policies in nursing homes should focus on the residents' well-being, identity, growth, safety, security, autonomy, meaning, and joy (J. Heid-Grubman, R. Priest, C. Ende, D. Hyde [Presenters], live webinar, October 23, 2012).

Challenges Identified With Implementing Person-Centered Care

Implementing person-centered care has been challenging for nursing homes. Fifty percent of nursing homes in 19 states participated in the Advancing Excellence in America's Nursing Homes Campaign's goals to improve their nursing home culture by year 2010 (n.d., "History and Milestones"). However, the level of actual culture change commitment has been questionable (Kapp, 2013). Committing to person-directed care that embraces residents' and staff members' autonomy versus making "cosmetic touches" at a facility is a gap that is occurring in some nursing homes (Kapp, 2013, p. 719). Only 5% of nursing home directors stated that their nursing home had completely transformed their nursing home cultures to include person-centered care according to a survey by the Commonwealth Fund's 2007 National Survey of Nursing Homes (Doty et al., 2008).

The ability to operationalize a culture that embraces person-centered care has been slow to develop in nursing homes largely because of lack of knowledge about culture change and person-centered care and because of disagreement in how the culture

can be changed in nursing homes (Koren, 2010). A lack of clarity in what culture change means and methods for measuring factors contributing to culture change, including person-centered care, have added to the causes of slow growth in culture change (Crandall et al., 2007; Rahman & Schnelle, 2008). Increased effort is necessary for involving residents in the nursing home culture.

A second concern of nursing homes is fear of violating state and federal regulations when transforming nursing homes to environments that are more like home. A challenge for nursing home staff members in operationalizing person-centered care is regulation expectations of state surveyors who tend to reinforce a model of care that focuses on clinical outcomes instead of care of residents using person-centered actions by staff members (Kapp, 2013; Koren, 2010; Levenson, 2009). Regulatory bodies should promote nursing home efforts for improving ways to deliver care instead of focusing primarily on assessments and care plans that tend to focus on the nursing tasks of caring for residents.

A third barrier is staff members' (including nursing home administrations) lack of value in a person-centered care philosophy (Miller et al., 2010). A change in state surveys to target assessments of "deep practice" that captures person-centeredness versus environmental practice could promote nursing homes to focus more on person-centered care strategies in their environments (Crandall et al., 2007, p. 53). Deep practice may begin when staff members value a person-centered care philosophy. Ways to assist nursing homes in implementing person-centered care was revealed in a project involving nine nursing homes in The Best Practices Initiative supported by the Hartford Center of Geriatric Nursing Excellence in 2007 (Crandall et al., 2007). The Best Practices Initiative

project revealed predictors of success for integrating person-centered care in nursing homes. Findings of the this project showed that three nursing homes accomplished significant progress, four nursing homes made important progress, and two nursing homes achieved minimal progress in implementing person-centered care practices. Revising mission statements, policies, and procedures and providing education and training practices occurred in the three nursing homes with significant progress in implementing person-centered care. A lack of actualizing and retaining culture changes occurred when four of the nursing homes focused on environmental components of the nursing home instead of the in-depth practice of care considered most important in person-centered care strategies. These four nursing homes revealed moderate or minimal transformation toward implementing person-centered care (Crandall et al., 2007). There were no changes reported in two of the nursing homes with staff members who did not view person-centered care as a core value.

Parallel with lacking value of person-centered care is the standpoint that nursing home staff members traditionally have used medical and custodial models of care under the direction of a hierarchical structure (Koren, 2010; Wiener et al., 2007). Miller et al. (2010) found that 93% of long-term care specialists comprised of nursing home care providers, consumers, state and federal officials, researchers, and others who participated in their study were familiar with person-centered care principles. The participants who were most familiar with resident-centered care and the culture change philosophy described resistance of leadership as the most significant barrier to implementing person-centered care. Cost was the most significant barrier to integrating person-centered care according to participants who were not as familiar with resident-centered care and

culture change. However, cost may decrease in nursing homes using person-centered models of care. Reduced staff turnover and decreased use of supplies, medications, and nutritional supplements led to lower costs when the Crestview Nursing Home in Missouri successfully implemented person-centered care (Rantz & Flesner, 2003). Baker (2007) asserted that reorganization and forming relationships are a key component to transforming cultures and add no costs.

Wiener et al. (2007) pointed out that nursing home models using innovative methods to change their culture become less hierarchical in structure and improve the quality of services; however, successful implementation of these innovations is rarely found in nursing homes. Further understanding about the language used to describe person-centered care strategies is necessary for promoting clarity (Brownie & Nancarrow, 2013).

Lastly, in traditional nursing homes, the focus on change has centered on payment incentives based on physical care of residents and organizational physical upgrades instead of the well-being of residents (Koren, 2010). However, currently a shift of payment incentives through grants and tax credits are provided for nursing homes with a goal to adopt person-centered care environments (Koren, 2010).

Even though the challenges of implementing person-centered care in nursing homes have been daunting, there is an increasing awareness that deinstitutionalizing nursing homes includes a delivery of person-centeredness where the residents' needs and preferences are the first priority in care (Baker, 2007; Doty et al., 2008) and the regimented environments of nursing homes are changing (Kapp, 2013). The research findings support Baker's (2007) assertion that making residents' desires the highest

priority opposed to focusing mostly on efficiency of care represented in clinical outcomes is finally emerging. The results of the Commonwealth Fund 2007 National Survey of Nursing Homes revealed that nursing homes with successful integration of person-centered care had improved occupancy rates, costs in operations, and staff retention (Doty et al., 2008). Research findings have revealed evidence for using person-centered strategies, and the development of various instruments for evaluating person-centered care is emerging. Yet, various challenges remain in implementing person-centered care (See Table 3).

Table 3

Research Findings: Implementing Person-Centered Care in Nursing Homes

Author	Research Method	Findings
Burack, Reinhardt, & Weiner (2012)	Quantitative	Providing choice in leisure activities was positive for residents. Providing choice for waking, eating, and going to sleep at night revealed little difference with implementation of person-centered care using the Duncan Choice Index tool. These specific activities required more of staffs' assistance. Residents' perceptions of choice, long-term, were not supported when implementing person-centered care.
Edvardsson & BA Hons (2010)	Quantitative	A comparison of 12 instruments was studied for measuring person-centered care. Eight of the tools evaluated nursing home care, three evaluated hospital care, and one of the measures evaluated dementia. Nine of the 12 instruments had not been used in research. Additional research studies integrating instruments for measuring person-centered care was suggested.

Table continues

Edvardsson et al., (2011)	Quantitative	<p>Descriptions of the effects of person-centered care strategies lack clarity. Implementation of person-centered care has been challenging due to a lack of clarity. The Tool for Understanding as Individual Persons (TURNIP) was developed and tested for assessing person-centered care interventions. The TURNIP revealed validity and reliability for increasing staff members use of person-centered care practices.</p>
Edvardsson et al. (2013)	Qualitative	<p>Staff members in 26 long-term care facilities participated in descriptions of how they facilitated person-centered care. Engaging residents occurred by offering residents' choices of activities, and listening and accepting the residents' points of view. Meaningful living was promoted when residents were encouraged to do things they enjoyed doing such as involving them in tasks that they enjoyed in the nursing home and creating activities that were interesting to them. Promoting pleasurable living was enhanced when staff members did "little extras" that residents appreciate (p. 4) and created special occasions such as dinners and dances. Promoting personhood surfaced when staff members described their focus on residents' meaningful life stories. The stories helped staff members to view the resident as a person, causing them to call the resident by name and offer greetings.</p>
Grosch, Medvene, & Wolcott (2008)	Quantitative	<p>Person-centered care behaviors were assessed for students enrolled in a certified nurse assistant training program. The intervention group had completed a person-centered care educational program. The results revealed the educational program</p>

Table continues

ineffective in promoting the CNAs to use person-centered care; however, CNAs who provided care with positive regard and choices for residents possessed interpersonal skills that supported a sense of relationship with residents. Nurses' role-modeling and CNAs evaluating their own video-recordings were suggested as methods to train CNAs about person-centered care.

McCormack,
Dewing et al.,
(2010)

Quantitative

There are insufficient methods for evaluating person-centered care described in the literature. Nursing outcomes in person-centered care environments were evaluated by RNs using the Person-Centered Care Nursing Index. A democratic work environment where team-working, workload and time management, and positive work relationships led to the development of person-centered cultures that were determined necessary for implementing person-centered care in care settings for older persons.

Medvene &
Lann-Wolcott
(2010)

Qualitative

CNAs responded to scripts and questions about communication strategies used when caring for residents. Communication methods using positive regard where CNAs developed relationships that revealed connectedness with the residents that revealed a "being in relationship" with the residents (p. 48). Education should focus on teaching strategies of person-centered care instead of behaviors of person-centered care. Further study is needed about relationships between staff members and residents in nursing homes.

Table continues

Rosemond (2009)	Qualitative/ Quantitative	Effective implementation of person-centered care occurred when a climate of person-centeredness emerged where management used cultural sensitivity and integrated person-centered expectations into the daily operations of eight nursing homes. Financial support, stability of the organization, time permitted for person-centered care training, and manager support were not found to be associated with effective person-centered care implementation.
Rosemond, Hanson, Ennett, Schenck, & Weiner (2012)	Qualitative/ Quantitative	Nursing homes' commitment to integrate a person-centered care project using the following methods explained effective implementation of person-centered care in eight nursing homes: (a) completely revising dining programs; (b) providing nursing assistant teams with direction for person-centeredness; (c) using communication by management with direct involvement in person-centered changes; and (d) obtaining climate changes based on visibility of management in person-centered groups.
Rosvik et al. (2011)	Qualitative	Integrating person-centered care in nursing homes was considered challenging. The concepts of person-centeredness are complex due to the challenge of recognizing the resident as a person with an individual personality and life history. Using a VIPS (Value for the experiences of residents with dementia and their family; Individual person; Perspective of the person; enhance the person's Social confidence) Framework assisted nursing homes in using person-centered care for residents with dementia.

Table continues

Schnelle et al. (2009)	Observational	Twenty nursing homes participated in the study where staff members and residents were observed during morning care of three activities of daily living: transfer from bed, dressing, and dining. Residents' preferences were acknowledged when the residents stated their preferences; however, staff members most often provided care without communicating with the residents about their preferences during their activities of daily living. State surveyor citations were inconsistent with the study findings in the nursing homes. Further study about standardized protocol used by surveyors is needed.
Simmons et al. (2011)	Quantitative	Although nursing homes participated in culture change and provided in-services for staff about providing residents with choice, staff infrequently provided residents with choices during their care in the mornings. Residents seldom requested their own choices and instead, staff prompted the residents' preferences.
Sjogren et al. (2012)	Quantitative	Because of lack of clearly defined person-centered care concepts, there is need for additional testing of person-centered care instruments. Common concepts of person-centered care described in the literature are retaining personhood, using personal and life experiences and relationships during care, promoting a positive environment, focusing on relationships as well as tasks of care, considering the person's point of view, and involving family members during care. The Person-Centered Care Assessment Tool revealed validity and reliability for

Table continues

White et al. (2008)	Quantitative	improving accuracy in measuring the operationalization of person-centered care in residential care facilities for older persons.
Williams et al. (2011)	Quantitative	<p>Nursing home staff members thought they used a person-centered philosophy and person-directed care; however, they learned that they were not as person-centered care focused as they thought. A tool to assess use of person-directed care assisted nursing homes in understanding person-directed care and implementing changes. Eight domains of person-directed care were measured and six dimensions revealed significant correlation: personhood, knowing the person, providing autonomy and choice, comfort care, nurturing relationships, and a supportive environment. Consistency in assigned staff members caring for residents enhanced resident-centered care.</p> <p>Integrating residents' life stories, cultural experiences, personality, daily life patterns, values, needs, and preferences in care are necessary when practicing person-centered care. Automated photos of residents were displayed in residents' rooms to enhance person-centered care. Task focused and person-centered communication methods were recorded and measured. There was a significant increase in interpersonal communication between staff and residents after frames were displayed in the residents' rooms. Although residents' engagement initially increased, after three months engagement decreased.</p>

In summary, it is clear that implementing person-centered care has positively changed the culture and improved care in nursing homes. The research on

person-centered care described in Table 3 reveals incentives and gaps in the implementation of person-centered care in nursing homes. Empowering residents by assuring preferences, choices, individual expression of needs, and autonomy in care as described in person-centered care, are essential for improving the culture of care in nursing homes. It appears that there are recent intentions of capturing what matters to residents in person-centered care approaches in nursing homes; however, the association of person-centered care and residents' reporting for themselves things that matter to them have not been clearly described in the literature. Talerico et al. (2003) claimed that care must give emphasis to residents' self-determination when using a person-centered care approach. Person-centered care can change the experience of "institutional life" where residents have "no say" while living in nursing homes (Widby, 2009, p. 37). Listening to residents and permitting them choices are essential in practicing person-centered care in nursing homes (Widby, 2009). Identifying things that matter to residents while living in nursing homes may expand on person-centered care.

Residents' Satisfaction

Resident satisfaction surveys have been used in an attempt for nursing home care providers to identify what is important to residents in nursing homes (Advancing Excellence in America's Nursing Homes Campaign, n.d., "Resident and family satisfaction"). Resident satisfaction is the resident's view of the dimensions of life during her/his living in the nursing home (Sikorska-Simmons, 2001). Satisfaction or dissatisfaction occurs when the care performed by the provider confirms or disconfirms the patient's expectation of care (Smith, 2000).

Historically, residents' satisfaction in nursing homes has been associated with quality for improving operations in nursing homes (Castle & Elliott, 2010; Chou et al., 2003; Lee, Lee, & Woo, 2005; Lowe, Lucas, Castle, Robinson, & Crystal, 2003; Robinson et al., 2004; Ryden et al., 2000). Donabedian (1980) claimed that patient satisfaction should be the validation for quality of care because it reflects the patients as the authorities in describing their own values and expectations of care; however, it is challenging to determine quality based on satisfaction since patients' values and expectations of care vary.

Variables Measured In Satisfaction Surveys

Studies about satisfaction surveys used in nursing homes have typically targeted resident, facility, and/or staff factors for measuring structure, process, and outcomes (Chou et al., 2003; Cohen-Mansfield & Parpura-Gill, 2008; Lee et al., 2005; Rantz et al., 2001; Straker, Ejaz, McCarthy, & Jones, 2007). Examples of measures commonly used in satisfaction surveys in nursing homes include: resident factors such as age, level of dependency on care, and their satisfaction with care (Chou et al., 2003); facility characteristics reflecting resources available to staff; environmental factors such as number of beds and size of facility; financial and administrative provider characteristics including experience of leaders (Lucas et al., 2007); and staff conduct, staff support, policies, and resources (Cohen-Mansfield & Parpura-Gill, 2008).

Although assessments of structure, process, and outcomes of care have been correlated with satisfaction surveys, outcomes of care have continued to be central in the measurements of quality in nursing homes (Ryden et al., 2000; Smith, 2000; Wiener et al., 2007). Outcome measures provide residents, families, investigative agencies,

nursing home administrators, and staff with important data for assessing quality (Robinson et al., 2004; Ryden et al., 2000; Smith, 2000). Governmental regulations permit nursing home providers to implement their own structure and processes of delivering care. However, structure and process methods for delivering care in nursing homes need further attention. Second to the highest deficiency of food sanitation cited in nursing homes are quality of care measures at 30.4% and professional standards at 29.3% (Wiener et al., 2007).

While the focus of satisfaction measures has mostly been on outcomes, Forbes-Thompson and Gessert (2005) found interconnections among structure, process, and outcomes correlated with resident satisfaction during end-of-life care. Differences in processes and outcomes of care occurred as results of contrasting philosophies in two nursing homes which demonstrate that outcomes are dependent on existent structure and processes. Donabedian (1966) cautioned healthcare providers that although outcomes validate the effectiveness of care, restrictions occur in accurately assessing outcomes. Significant factors, other than medical care, may impact outcome measures. However, face validity may be questionable in outcomes that are difficult to measure such as patients' attitudes or satisfaction (Donabedian, 1966).

Including variables about cultural beliefs and values may add to the validity of resident satisfaction surveys. There has been a move for overall healthcare organizations to link culture with the structure, process, and outcome variables in quality initiatives. Culture reflects the values and beliefs of the organizational members (Glickman, Baggett, Krubert, Peterson, & Schulman, 2007). Including culture in quality initiatives promotes accountability, autonomy, and cooperative interdisciplinary care among all levels of

caregivers. The culture change efforts by the Pioneer Network have exemplified ways to build a quality culture as described by Glickman et al. (2007). Capturing residents' values and beliefs in satisfaction surveys may provide insight about the culture in nursing homes.

Methodological Issues with Satisfaction Surveys

The literature reveals ongoing problems with satisfaction surveys in nursing homes. Satisfaction surveys that are used to assess quality in nursing homes have revealed item inconsistency (Lee et al., 2005) and inadequate testing for validity (Castle et al., 2004). It is essential to consider data from surveys of residents, families, and nursing home staff then to develop themes for addressing concerns about satisfaction. Compiling data to determine a common measure of satisfaction in nursing homes may be an issue with accurately measuring satisfaction (Straker et al., 2007). Members of Advancing Excellence in America's Nursing Homes Campaign (n.d., "Implementation guide: Goal 7") have addressed satisfaction survey issues and have provided guidelines for nursing homes to utilize for improving satisfaction survey processes.

Secondly, describing the consumer of long-term care has been problematic (Castle & Elliott, 2010). Some surveys target family members as the consumers instead of the residents. These assessments of satisfaction by proxies have revealed limitations because of their general opinions about nursing homes or other factors that are not correlated to the care of residents (Castle, 2006; Straker et al., 2007). In addition, there has been a lack of congruence in residents' perceptions of satisfaction compared to the perceptions of nursing home caregivers and providers and family members (Castle & Elliott, 2010; Chou et al., 2003).

Thirdly, some participants may refuse to complete surveys or impose bias in their survey responses for a host of reasons. Representatives of Advancing Excellence in America's Nursing Homes Campaign (n.d., "Implementation Guide: Goal 7") acknowledged causes of residents' hesitation to report dissatisfaction due potential breach of privacy or retaliation when completing satisfaction surveys. Residents may fear reprisal even after being assured that staff would not be notified of their names when reporting dissatisfaction (Ryden et al., 2000), and residents attain adjustment and acceptance of the nursing home environment which have led them to not make their desires known (Housen et al., 2008). In addition, residents may lack understanding about the importance of providing information about their nursing home care (Castle & Elliott, 2010). Surveys tend to provide questions that are ambiguous or are more challenging for frail populations (Housen et al., 2008). Residents or family members may feel challenged when assessing satisfaction if they do not understand the dimensions of care (Housen et al., 2008). Ways to overcome these challenges include increasing awareness that residents can make their own choices within the nursing homes and that their perspectives are valued, providing information about nursing homes via the web, and implementing governmental mandates such as is occurring in the state of Ohio where satisfaction assessments are administered separately to residents and family members (Straker et al., 2007). Some nursing homes have used proprietary services to overcome issues with their satisfaction surveys (Ejaz & Castle, 2007).

A fourth concern exists about healthcare providers' equating quality of care dimensions with resident satisfaction. Although nursing homes are encouraged to use satisfaction surveys to measure quality, satisfaction and quality are separate constructs

according to Applebaum, Straker, and Geron (2000). Data generated from satisfaction surveys are not substitutes for the actual care or communication with patients. On the contrary, residents' stories may not capture essential data that reflects quality of care. It is essential that nursing home care providers understand the limitations of strategies used for assessing residents' satisfaction and realize that objective and subjective aspects of care are essential in satisfaction assessments (Applebaum et al., 2000).

Lastly, Castle et al. (2004) claimed that residents' input is seldom included in the development of nursing home satisfaction surveys and instead, surveys typically reflect the goals of nursing home administrations or most often represent the nursing home providers' views of what is satisfying to residents (Ryden et al., 2000). Satisfaction surveys typically created by academicians and experts in the nursing home industry do not include significant content areas that capture resident satisfaction in the assessments (Robinson et al., 2004). It is essential that assessments of satisfaction in nursing homes include residents' perspectives (Advancing Excellence in America's Nursing Homes Campaign, n.d., "Implementation Guide: Goal 7"; Straker et al., 2007; Wheatley et al., 2007).

Strategies Used to Improve Satisfaction Surveys

Nursing home providers have used various strategies for implementing satisfaction surveys. Satisfaction surveys of family members and staff also have been used to assess quality improvement (Goodson et al., 2008; Lee et al., 2005). Obtaining residents' input using cognitive interviews was a strategy that successfully determined how to restructure satisfaction survey questions to make them comprehensible for residents. Cognitive interviews comprised of a four-step process where the interviewer

asked participants to: (a) translate the questions for the interviewer, (b) share their feelings and beliefs about the content in the questions, and (c) reveal their attitudes about the questions. The fourth step occurred when the interviewer edited the questions to promote clarity in the satisfaction survey (Housen et al., 2008).

The CMS is currently improving surveys that provide assessments of quality and patient-centered variables. One suggested improved survey is the Nursing Home Consumer Assessment of Healthcare Providers and Systems (NHCAPS) comprised of three instruments: a questionnaire for residents to complete in person; a mailed questionnaire to short-term care residents, and a questionnaire for family members of residents. The survey was developed by the USDHHS AHRQ upon the recommendation of the CMS for improving the assessment of quality of care and quality of life for residents in nursing homes (USDHHS AHRQ, 2011). This survey provides data for reports for consumers who desire to assess nursing home quality prior to choosing a nursing home for services. The NHCAPS has been integrated by CMS for assessing nursing home quality nationwide.

Additionally, in October 2010 the CMS began requiring Medicare/Medicaid nursing homes to use a revised MDS, an instrument used by nursing homes to assess residents (Saliba & Buchanan, 2008; USDHHS CMS, 2010). This instrument, titled MDS 3.0, replaces the 2.0 version with the objective of capturing residents' voices by including direct resident interviews. The MDS 3.0 was tested in trials for validity and feasibility between 2003 and 2008. In the trials, residents' chose from a point response set (*very important, somewhat important, not important, important, but can't do—no choice, or no response or non-responsive*) to questions about topics considered by consumer and

provider experts important to residents in nursing homes. These topics included customary routine and activities and also the participation in assessment and goal setting (USHDDS CMS, 2010). The 3.0 version revealed reliability, accuracy, and usefulness, and it has been implemented in all Medicare- and Medicaid-reimbursed nursing homes beginning October 2010 (USDHHS CMS, 2010).

The Advancing Excellence in America's Nursing Homes Campaign established goals for nursing homes with the expectation that the survey responses of residents and family members were included within plans for quality improvement. In-depth questions that provide clarity about "meaningfulness of activities" and issues of concern for residents and families are included in the new objectives for guiding nursing home providers to improve their satisfaction surveys (Advancing Excellence in America's Nursing Homes Campaign, n.d., "Implementation guide: Goal 7," p. 10). Person-centered care and consistent assignment are two goals that have recently been added the new goals to enhance quality of care in nursing homes (Advancing Excellence in America's Nursing Homes, n.d., "The New Goals").

It is critical that resident satisfaction surveys are standardized and thorough to assure that the surveys measure what is important to residents (Advancing Excellence in America's Nursing Homes Campaign, n.d., "Implementation guide: Goal 7"). Applebaum et al. (2000) asserted that examining satisfaction in long-term care must rely on "hearing the voices" (p. 11) of the residents or consumers; otherwise, assessing satisfaction is limited. In-person or face-to-face interviews have been deemed the "gold standard" for measuring satisfaction (Advancing Excellence in America's Nursing Homes, 2010, p. 7). Disadvantages of in-person or face-to-face interviews include the length of time needed

for interviewing residents, the essential training required for interviewers, lack of residents' openness to questions, concerns of potential breaching of confidentiality, and the higher costs created when surveys are conducted by organizations outside of the nursing homes (Wheatley et al., 2007). Nevertheless, face-to-face interviews that reveal valid and reliable data are well worth the administration costs (Wheatley et al., 2007).

Overall, resident satisfaction surveys have been shown to be valuable tools although additional work lies ahead in constructing ideal satisfaction instruments that capture things matter to residents. Concerns about satisfaction surveys administered in nursing homes continue to exist. However, satisfaction surveys have been key instruments in the focus on quality of care and quality improvement (Advancing Excellence in America's Nursing Homes, n.d., "Implementation guide: Goal 7"; Castle et al., 2004; Lee et al., 2005; *Nursing Home Reform*, 2007; Rantz et al., 2001) and in providing information that consumers need in order to make sound choices when selecting nursing homes (Lowe et al., 2003; Wheatley et al., 2007). The literature also reveals that creators of surveys are attempting to capture residents' views in order to further improve quality of care (Advancing Excellence in America's Nursing Homes Campaign, 2010; Chou et al., 2003; Lee et al., 2005; *Nursing Home Reform*, 2007; Robinson et al., 2004; Straker et al., 2007; USDHHS CMS, 2013a). Housen et al. (2008) emphasized the need for focus on research that examines resident interviews that capture value of residents' preferences for planning individualized care. Finding items that matter to residents may reveal additional core measures for future satisfaction surveys. Nursing home healthcare providers may attain increased awareness of structure and process care

methods that are important during care when residents disclose things that matter to them in nursing homes.

Things that Matter to Residents

Carlsen (1988) discussed the common practice for caregivers to use “filtering and lenses” (p. 72) when applying normative data that represent typical standards in care. These data tend to lead caregivers to stereotype older persons and miss things that tell “what a person is about” as described by Buhler (1977, p. 20). Carlsen stated, “We miss the essence of individual meaning putting our clients at the mercy of our manipulations, imposition, and intervention” (1988, p. 72).

The small number of studies about things that matter to residents centered on quality of life in nursing homes (Burack, Weiner, Reinhardt, & Annunziato, 2012) and satisfaction measures (Ghusn et al., 1996; Kane et al., 1997). Quality of life domains that were found to matter most in promoting satisfaction for residents in nursing homes included dignity, spiritual well-being, and food enjoyment (Burack, Weiner, Reinhardt, & Annunziato, 2012). Domains of meeting expectations, respect, feeling needed, and self-perceived health were found significant in correlation with life satisfaction in residents in two Veterans’ Affairs Nursing homes (Ghusn et al., 1996). Choice and control were domains found to significantly matter more to residents in nursing homes over other matters such as daily life and care domains in the study by Kane et al. (1997).

Persson and Wasterfors (2009) interviewed staff members in three nursing homes who stated that they rendered care to meet the needs of the nursing home establishment over the needs and desires of residents. A “folk logic” (Persson & Wasterfors, 2009, p. 2) for care existed where staff members defended their routine care with ideal reasons and

justifications for the ways care was expected to be rendered for residents. Examples discussed in the study included nursing home staff placing residents in bed or showering residents at certain times because of the staff's schedule. Staff members also trivialized residents' complaints and those residents who did not complain were considered "content and happy" (Persson & Wasterfors, 2009, p. 6). It may be possible that problems or other matters for residents in the nursing homes were "invisible" to staff members (Persson & Wasterfors, 2009, p. 10).

Misiorski (2011) interviewed residents about what mattered most to them regarding their quality of life while living in nursing homes. Receiving competent care, having freedom to make choices, giving and receiving relationships, and engaging in meaningful activities were categories that emerged from the resident interviews. Residents expressed the desire to have choices in simple things such as softer towels, better toilet paper, family style dining, and memorial services provided for other residents who died in the nursing homes. Misiorski claimed that giving in addition to receiving care improves relationships and minimizes the risk of learned helplessness where persons feel a lack of control and dependence on others for decision-making and guidance. Meaningful activities alleviate boredom. Residents who are sleeping in chairs, sitting in hallways, and lining up as they wait for mealtimes reveal boredom in the environment. Misiorski believed that the key to eliminating boredom is to get residents involved in planning activities that matter most to them.

Research Implications for Describing Things That Matter to Residents

The research findings revealed improved quality of care for residents when person-centered care strategies were implemented in nursing homes. On the contrary,

different philosophies and language used to identify person-centered care has led to lack of clarity about the concepts of person centeredness. Further research is necessary for knowing what things matter to residents in nursing homes. The goal of this qualitative descriptive study was to describe things that matter to residents that may improve their care. This study aimed to expand on the state of the science in person-centered care strategies and methods for assessing residents' satisfaction in nursing homes. Knowing about things that matter from residents' perspectives may add clarity to the concepts of person-centered care and methods of evaluating residents' satisfaction in nursing homes.

The literature shows strategies to promote creative aging by integrating meaning-makings or the things that matter for older persons during care. These strategies provide a framework that could expand on person-centered care by integrating what things residents describe matters to them in nursing homes. The first step to describing things that matter to residents is to realize that things that matter are unique and essential for each individual (Carlsen, 1991). Assuring an environment that permits residents to determine and include things that matter during their care could improve residents' living experiences in nursing homes. Initiating person-centered care and assessing satisfaction that capture things that matter to residents may promote understanding about quality of care from residents' perspectives.

Nurses who encourage residents to share things that matter may assist in actualizing residents' self-determination that is a right of residents while living in nursing homes. Using effective interaction that promotes residents' self-determination may facilitate residents' partnership in care which is important within person-centered strategies. Knowing what matters to residents may assist nursing home providers to

improve the accuracy of satisfaction surveys by eliminating the risks of residents' biased responses, fear of breached confidentiality and reprisal, and perceptions that their voice does not matter or is not heard.

Secondly, nurses are in prime positions to provide residents with knowing the how and why or the rationale of care rendered in nursing homes. Residents' knowing the rationale for how or why events take place may prompt residents to find significance in their ordering of things that matter while living in nursing homes. In addition to providing the rationale of events, it is critical that nursing caregivers provide residents with choices in these events that embrace things that matter as designated by residents instead of residents being given choices that reflect what matters to caregivers or the nursing home establishment.

Lastly, residents may be more likely to attain creative aging while living in nursing homes if what matters to them is directive in their care. A nursing home environment where residents are encouraged to give as well as receive care, have freedom to determine their own choices, and engage in what it is that matters most to them has revealed that residents feel an improved quality of life. Care of residents that includes things that matter to residents will enhance nursing care practice and improve quality of care in nursing homes.

Summary

Governmental agencies, healthcare providers, caregivers, and consumers have made known their expectations for a continued upgrade in quality of care in nursing homes. Person-centered care strategies and satisfaction surveys are two major approaches that have led to improved quality in nursing homes. Even so, ways nursing caregivers

render and assess care are under scrutiny in most nursing homes. Assuring that things that matter to residents are included in care and assessments of satisfaction may add to current quality improvement measures.

A major cause for the slow growth in changing the culture that includes person-centeredness is the challenge to provide clarity and promote understanding about ways to implement person-centered care in nursing homes. Knowing what things matter to residents may assist in advancing nursing care in more intentional person-centered ways.

Understanding that the resident is the consumer of satisfaction and assessing things that matter to residents in satisfaction surveys may add insight for measuring structure and process that may be missing in satisfaction surveys. Satisfaction surveys that include things that matter to residents may enhance their understanding of survey questions. Residents responding to questions that they understand will improve the validity of satisfaction assessments.

An increased aging population and complexity of care in addition to the higher expectations of consumers will add to the demand for an increasing number of ideal nursing homes. Knowing about things that matter to residents will uncover what residents are about, which is in juxtaposition with person-centered care strategies and the need for accurate assessments of care practiced in ideal nursing homes. Including things that matter to residents in nursing care will assist nursing educators to prepare students to perform quality of care that residents rightfully expect and deserve while living in nursing homes.

CHAPTER THREE. METHODS

Design

Qualitative research evolves from researchers' interests about social or human problems (Creswell, 2007). Researchers identify these problems from within groups of individuals or within an individual then explore the problems in the natural settings. Natural settings provide the researcher with an opportunity to observe the participants react within their actual context as they describe the issues being studied (Creswell, 2007). The research design continues to emerge throughout the research process. All qualitative research is interpretive at some level and the concentration should be more on what arises from the study versus claiming a method (Sandelowski, 2010a). Any phase of the research process may warrant a shift in the question asked, the location of sites for the visits, or the actual data being collected according to Creswell (2007). Maxwell (2005) used the term *interactive model* when describing qualitative research design and explained that interconnectedness and flexibility are key components for establishing the goals, conceptual framework, research questions, methods, and validity.

Qualitative research provides an opportunity for the observer to make connections while viewing participants' worlds during conversations and taking other actions that include recording field notes or memoranda in the natural setting of the participants (Denzin & Lincoln, 2005). The goal of qualitative research is to employ a method that will bring about an enhanced understanding of what is studied. In concurrence with Creswell (2007), Denzin and Lincoln (2005) and Sandelowski (2010a) asserted that although the researcher anticipates using a certain design, the research design that best fits the study will emerge during the research process.

Pilot Study

In an attempt to understand residents' perceptions of quality of care in nursing homes, I conducted a pilot study from February through July of 2009 in nursing homes where residents lived (Reimer, 2009). The purpose of the pilot study was to determine if the interview questions would elicit residents' rich descriptions of how they experienced quality of care in nursing homes. A Heideggerian interpretive phenomenology method was used to explore residents' perceptions of quality nursing care in nursing homes. Martin Heidegger's philosophy focuses on the lived experience of being in a world where meaning derives from existence in the past, present, and future (Heidegger, 1927/1962). Interpretive phenomenology embraces an ontological view of seeking to understand how an individual has something or perhaps nothing to know based on the person's reality of the world (Benner, 1994).

Recruitment of Residents for Pilot Study

After receiving Internal Review Board (see Appendix B) approval, I recruited residents aged 65 or older who lived in the long-term care section of three Midwest nursing homes using a purposeful sampling method. Residents who agreed to participate in the study also provided written consent for release of health information comprised within the MDS assessment that provided information for a cognitive assessment tool, the MDS-Cognition Scale (MDS-Cogs). The MDS-Cogs has shown significant validity and reliability specifically for cognitive assessments of residents in nursing homes (Hartmeier, Sloane, Guess, & Koch, 1994). In person, I asked residents with scores that revealed no cognitive or minimal cognitive impairment to participate in the pilot study. It was justifiable to choose residents who demonstrated understanding of consent and

participation in the interviews. Because a significant portion of residents in nursing homes have some level of cognitive impairment, a need to access this population occurs because there are a limited number of residents who are not cognitively impaired in nursing homes, and interviews should represent information shared by the typical population of residents in the long-term care sections of nursing homes. The MDS-Cogs was not used in the dissertation study because of the updated MDS 3.0 that occurred in October 2010. No studies testing validity or reliability on the MDS-Cogs using the updated MDS 3.0 resident assessment data was found in the literature. I was not confident using the MDS-Cogs since there were no studies found with testing the MDS-Cogs scale based on the revised MDS assessment data. Therefore, I chose another instrument, the Montreal Cognitive Assessment (MoCA; see Appendix C) for assessing residents' cognitive ability for participating in subsequent interviews. The MoCA is described later in this chapter.

Sample for Pilot Study

For the pilot study, I interviewed four residents with an idea that I might learn about residents' experiences of quality nursing care in nursing homes. The charge nurses of the long-term care sections provided a list of residents whom they stated did not have severe cognitive impairment and would be able to discuss participation in the study. The charge nurses were overseeing the care of all of the long-term care residents in each facility. Having the charge nurses' list of residents provided an opportunity for me to select from the overall long-term care residents whom the charge nurses felt were capable of providing consent to access their medical records and participate in the study. During the first visit with each resident, I introduced and described the study. I shared the

purpose of the study, procedures of audio-taping and analyzing data, the risks and benefits, and confidentiality with each of the four residents. Iterating to the residents that they were invited to participate in the study, I explained that they could opt to not participate in the study at all or could withdraw from the study at any time. After the residents agreed to participate in the study and provided consent for me to access their MDS record, I completed the MDS-Cogs for each resident. The four selected residents met the criteria for no or mild cognitive impairment in the MDS-Cogs assessment.

Interview Method for Pilot Study

Semi-structured interviews began with presenting the following statement to each of the four residents: Tell me about a time when you received good care here in the nursing home. Subsequent questions presented to each resident included asking the resident:

- for examples of what caregivers did that made care good,
- how caregivers assisted the residents with activities that the residents found to be fun, and
- how staff showed they cared about the residents.

The interviews increased in depth as the residents gained trust and comfort in sharing their experiences. The residents described feeling loss when they gave up their independence and contact with significant others upon entering the nursing home, good feelings about helping other residents especially those residents who were dependent on care, presence in fun times although the fun times were very individualized, desires to maintain peace with caregivers by not saying anything when feeling frustrated about care,

and being sensitive to caregivers who knew how to care for them in ways the residents preferred.

Data Analysis and Preliminary Results of the Pilot Study

The beginning data analysis occurred with the assistance of members in a qualitative research course comprised of student researchers and nursing professors also studying Heideggerian interpretive phenomenology at Indiana University School of Nursing. Student researchers and professors in the qualitative research course assisted me in reading and sharing important passages identified in the transcripts of the interviews where the residents described important experiences that expanded beyond the concept of good care received in the nursing homes. My field notes, recorded as I observed the residents during the interviews, were shared with the student researchers and professors in the course. Across the four transcripts, I found clusters of data with the following themes that emerged: (a) feeling loss while living in the nursing home, (b) desiring to help other residents (c) finding presence in fun times, (d) maintaining peace with caregivers, and (e) being sensitive to individualistic care. The initial interview statement, “Tell me about a time when you received good care here in the nursing home” revealed broad perspectives of residents’ experiences that were important in nursing homes. The residents spoke less about their experiences of good care and instead targeted other things that seemed more important to them. Examples of broad perspectives taken from residents’ stories shared during the pilot study included descriptions of the nursing home as “home that’s not home,” the clown who visited weekly and asked a resident to dance, staff who didn’t seem to understand that a resident felt belittled when repeatedly encouraged to lead a singing group, the experience of feeling compelled to help other

residents who were more dependent than the resident being interviewed, and frustration as a result of nursing staff who didn't acknowledge the resident's desire to have the bedspread straightened and the trash emptied routinely.

Summary of the Pilot Study

This pilot study prompted me to think seriously about the need to personalize care in ways that capture things that are important to residents. I believe that most nursing caregivers aim to do the right things for residents during their care; however, the pilot study revealed that it was common for nursing caregivers to miss things that seemed to be important to residents in the nursing home. I began to wonder what other things important to residents might enhance their care and sense of well-being in nursing homes.

Although the themes did not clearly reflect the specific focus on quality of care in the pilot study interview findings, the Heideggerian interpretive phenomenology was a useful method in learning about experiences that were important to residents while living in nursing homes. Creswell (2007) explained that qualitative research involves an understanding that the researcher may find it necessary to shift or modify the research design during any phase of the research process. The research design is dependent on an optimal way to find information and to gain understanding about the concerns or problems disclosed by participants. A qualitative description provided a method for me to ground the data in the actual findings which residents described as mattering to them in nursing homes. The qualitative description directed me to remain ontological and to use lower inference with less deep interpretation in comparison to the Heideggerian interpretive phenomenology method. Sandelowski (2010b) described qualitative description as a method to keep findings close to what the participants described.

Knowing about things that matter to residents may provide direction for revisiting the Heideggerian interpretive phenomenology method in a future study about how residents experience the events that matter to them in nursing homes.

Qualitative research methods require researchers to use an iterative approach where sampling, data collection, analysis, and interpretation occur together. The aim of the qualitative descriptive method is for researchers to describe data that is close to the actual findings, yet draw inferences that lead to some idea or concept for new understanding versus replicating the data (Sandelowski, 2010a). The qualitative descriptive approach is less interpretive than other qualitative methods used to uncover participants' experiences. Without imposing preconceived bias about what things matter to residents in nursing homes, it was essential to remain aware that the data might or might not support current leading strategies for improving quality of care, such as using person-centered care or assessing care using satisfaction surveys (See Figure 4).

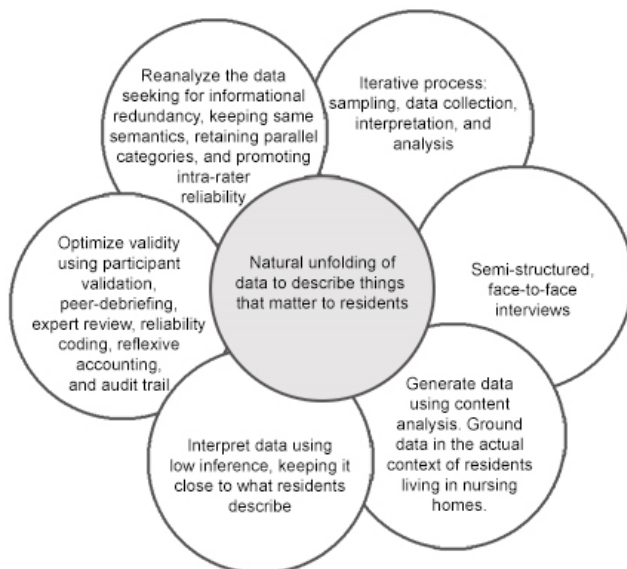


Figure 4. The qualitative description method is an iterative process using low-inference interpretation.

The research design that best fit this study was a qualitative method. Sampling, data collection, analysis, and interpretation occurred together using an iterative process. The natural unfolding of data with low inference interpretation kept the data close to the residents' descriptions of things that mattered to them while living in nursing homes.

Theory

Researchers performing qualitative description may begin with a theory or framework to guide their studies; however, it is necessary for researchers to remain cognizant of their theoretical preconceptions and be aware that the data may bring forth new theoretical frameworks that support the study (Sandelowski, 2010b). The theory of Health as Expanding Consciousness provided me with guidance as I developed questions and prepared for the interviews. The concept of presence in this theory enhanced my understanding about essential partnerships that must develop between the residents and myself as the researcher.

Newman described expanding consciousness as the person's "pattern of the whole" that affects the person's feelings and meanings (2008, p. 33). Pattern is the person's awareness as a whole being in an environment and embraces the person's capability to interact in that environment. Developing open-ended questions promoted a natural unfolding of the data when I encouraged residents to share their own thoughts about what matters to them while they are living in nursing homes. Providing ample time to become acquainted and establishing rapport with the residents during all stages of the research process assisted the residents in comfortably responding to the questions. I remained sensitive to the residents' responses to the interview questions and took note of the residents' nonverbal behaviors and attitudes that provided additional insight during

the interviews. Newman's theory of Health as Expanding Consciousness emphasized the importance of interconnectedness with the residents. A person is more apt to interact in a complex environment when the person achieves an increased level of consciousness as a result of person–environment interaction. Becoming one with the client as described by Newman (1994) facilitated trust and development of relationship. Expanding consciousness represents health when the person discovers something enlightening that transforms the person in some manner. Residents may gain empowerment when they feel welcomed to openly share things that matter to them that may impact their care and perhaps the care of other residents. Assuring residents that things that matter to them are important for improving care may enhance their self-direction in care. Newman's theory represents the art of caring that is essential for establishing a trusting relationship with the residents. The theory represents a participant–researcher relationship that promoted validity for this study.

Human Subjects Approval

This research study with residents in nursing homes remained in accordance with the Indiana University–Purdue University Indianapolis (IUPUI) Institutional Review Boards (IRB) and the Health Insurance Portability and Accountability Act (HIPAA) guidelines. Three nursing homes administrations in the Midwest provided consent for being sites for the interviews. The letters of consent by the nursing home administrators (see Appendix D) were forwarded to the IRB. The IRB requested justification for using cognitively impaired participants in the study and requested participant consent for the inclusion of cognitively impaired individuals, an assent that required thorough explanation and clarity provided to each of the residents about the research process prior

to their making a decision about participating in the study. The IRB approval for the pilot study was received January 2009 and subsequent approvals were received with the final approval made in July 2013 (see Appendix B).

Risks of Taking Part in the Study

The residents were informed that the risks of the study included possible anxiety or stress as a result of their reflecting on things that matters to them in the nursing home. Another risk of participating in the study was the residents' becoming tired during the interviews. The residents were assured that they could refuse to answer any questions, take breaks as desired for any amount of time desired, or stop participating in the study at any time during the interview without penalty. Another potential risk could be a loss of confidentiality; however, as the researcher, I protected the residents' privacy and confidentiality as much as possible before, during, and after the interviews. The privacy and confidentiality of each participant were protected as I obtained the cognitive assessment information then analyzed and stored the information. Each interview was conducted in a private area designated by the resident in the nursing home wherein the resident resided. Information obtained during the conversations with residents was not shared with nursing home staff members. I secured data by storing it electronically using passwords. The transcripts were stored in locked file cabinets. The interviews were scheduled so as not to interfere with any of the residents' ongoing therapy or regimens.

Benefits of Taking Part in the Study

The residents were informed about benefits of participating in the study. The residents were informed that they could contribute ideas that nurses could use to improve care in nursing homes. Another benefit for residents in the study was an opportunity for

them to have a voice in describing things that matter to them in the nursing homes. The residents were informed about the purpose of the study, which was to gain knowledge about things that matter to residents in order to assist nursing caregivers to improve nursing practice in nursing homes and to enhance nursing.

Protection

Assuring the residents that their participation in the study was voluntary and that they could refuse to take part or leave the study at any time intended to promote their understanding that they were not committed to participate unless they desired to do so. I informed the residents that if they chose to exit from the study, they would experience no penalty or loss of benefits to which they were entitled nor would it affect the current or future relations with the nursing home wherein they resided. When I obtain informed consent from the residents who agreed to participate in the study, I also obtained consent for completing the cognitive assessment tool with each of them. During the initial meeting with the resident, which was prior to the interview, I explained that I would not share actual names, birth dates, or any other identifiable information obtained from them with any of the nursing home staff, administration or other residents. The cognitive assessment information obtained from the residents did not include identifiers such as names or birth dates. Making it known to the residents that I would not share their agreements to participate or not to participate in the interviews with nursing staff members or other residents was important assuring their feelings of confidentiality. The name and telephone number of the principal investigator were included in the copies of the consent forms that were provided for the residents (see Appendix E). I encouraged the

residents to report questions or concerns about the research process to the principal investigator or members of the IRB and provided that contact information.

During the interview, I did not share the residents' conversations with any of the staff members, administration, or other residents at the nursing homes. The residents chose their rooms as the private place for the interviews to occur even though they acknowledged that staff members potentially could enter the rooms during the interviews. I scheduled the interviews for dates and times that the residents indicated were convenient for them. I kept anything that the residents stated during the interviews de-identified as I shared the information with my dissertation committee members. I explained to the residents that I would also keep their information de-identified in the study, at educational offerings or conferences, and in publications.

I reminded the residents prior to and during the interview process that they could: (a) withdraw from the study at any time, (b) take breaks as they desired, (c) end the interview at any time, and (d) refuse to answer any questions presented during the interview without penalty or reprisal. I also permitted the residents any desired amount of time that they needed to make a decision about participating in the study. I provided an in-depth explanation about the study and the interview process prior to the time that the residents gave informed consent and assent.

After the interviews, I kept the residents' recorded conversations accessible only to myself as the researcher, the dissertation committee members who agreed to assist in analyzing the data, and any assistants who assisted in transcribing the interviews. Residents' names, cognitive assessment information, and the names of the nursing homes were not shared with any other persons viewing the study results except as required by

law and the IRB. In addition, I destroyed the audio tape recordings after completion of the study.

Sample

I used purposeful sampling for inviting residents to enroll in the study. In narrative studies, the sampling focus is on residents who have stories to share about the problem being studied (Creswell, 2007). The goal of purposeful sampling in qualitative studies is to generalize from the cases or about the actual cases studied instead of correlating generalizations from the study samples to populations that is the goal in probability sampling (Sandelowski, 2010b).

Charge nurses of the long-term care units provided a list of residents who they determined had adequate cognitive awareness to provide consent and to participate in the study. I approached charge nurses of the long-term care sections of the nursing homes because the charge nurses in the three nursing homes oversee the overall long-term care residents. Selecting residents from the overall long-term care residents provided me with an opportunity to utilize maximum variation sampling with obtaining potentially diverse residents within the long-term sections of the nursing homes. I approached the individual residents on the list, introduced myself, and asked them if they were interested in hearing about the goal of my study then invited them to participate in the study. If the residents on the list expressed interest in participating, ample time was provided for an in-depth description of the study at that time or at a scheduled time that the resident determined was more convenient. The residents also designated where we would meet to discuss the study and their participation in the study. Each of the residents suggested that we conduct the interview in the resident's room.

My goal was to interview five to ten residents for this study. Flick (2007) stated there is no established number of participants required for completing a qualitative research study, and the desired number of participants enrolled in studies will vary according to the research topic. Sandelowski claimed that research interviews in a qualitative description become complete when the findings have been accounted for in the data where the research can answer the research questions in a systematic manner. Additionally, the researcher is able to raise new questions and form new ideas when the data is saturated (Sandelowski, 2010b). The researcher and auditors of this study agreed that data saturation occurred when the residents' interviews revealed repeated passages of things that mattered in nursing homes and new questions and ideas developed about things that matter to residents in nursing homes. These new questions and ideas are described in Chapter Five.

Inclusion/Exclusion Criteria

I invited residents aged 65 or older who resided in the long-term care sections of nursing homes to participate in the study. The residents agreed to complete a cognitive assessment, the MoCA, in order for me to determine if the residents had no or mild cognitive impairment. Because this study pertained to residents in nursing homes, it was justifiable to choose institutionalized residents. The MoCA revealed strong validity and reliability as well as high sensitivity and specificity for cognitive impairment and Alzheimer's dementia compared to the Mini-Mental Status Exam, which is the most extensively used tool to assess cognitive impairment and dementia (Nasreddine et al., 2005). I chose the MoCA because psychometric testing has shown evidence of strong validity and reliability as well as high sensitivity/specificity when tested on older

persons with mild cognitive impairment or mild dementia. It is relatively simple to use and takes approximately ten minutes to administer (Nasreddine et al., 2005).

Residents who agreed to complete the MoCA screening and obtained a score of 26–30 indicating no cognitive impairment, or 18–26 indicating mild cognitive impairment were eligible to participate in the study. Residents whose MoCA scores revealed moderate to severe cognitive impairment did not meet the criteria. One resident invited to participate in the study did not meet the MoCA criteria; therefore, I gently informed him that it was necessary for him to meet specific criteria in order to participate in the study. He verbalized understanding and demonstrated no disagreement with the assessment. Residents in the study agreed to share things that mattered to them in nursing homes. Residents who demonstrated understanding of consent and agreed to participate in the interviews, revealed no or mild cognitive impairment according to the MoCA score, were willing to share the things that mattered to them, spoke English, and committed to the time necessary for the interviews (approximately 60 minutes each for a first visit and a second visit), were eligible to participate in the study.

Setting and Sampling Recruitment

I selected residents from the three Midwest nursing homes where the pilot study had been conducted. The nursing homes were Medicare- and Medicaid-reimbursed facilities that provided short- and long-term care. Residents chosen for the study resided in the long-term care section of the nursing home. Residents in long-term care sections of nursing homes reside for more than 100 days where the level of care is considered less intense than skilled care that is rendered by nursing staff in the short-term units. The CMS refers to long-term care as *custodial care* or unskilled care where residents require

basic assistance with activities of daily living (USDHHS CMS, 2013b, “Custodial care,” section 110). It is common that residence in long-term care sections of nursing homes become the residents’ permanent residency.

Kane et al. (1997) selected residents who resided in nursing homes less than one year in addition to long-term residents in a cross-sectional study. Research studies tend to exclude short-term residents, and Kane et al. sought to determine if residents who were new in the nursing home would have different perceptions about living in the nursing home than those residents who were long-term. However, this study will focus on perspectives of long-term care residents who most likely will have permanent residency.

The sampling approach used in the pilot study worked effectively and was used for the study. The charge nurses of the long-term care sections of the nursing homes provided names of residents who were available to be invited to participate in the study. When residents agreed to participate in the study, ample time was provided for an in-depth description of the study, scheduled at a time determined by the resident. The study began with two residents selected from each of the three nursing homes. Repeated interviews with residents facilitated trust and provided validation of study findings (Creswell, 2007; Lincoln & Guba, 1985; Maxwell, 2005; Sandelowski, 1986). After the first scheduled interview with each of the residents, a recurrent interview with the residents provided an opportunity for residents to validate the first interview data. The time and location within the nursing home for recurrent visits with the residents occurred at the discretion of the residents.

Generating Data

Generating data occurs within a circular process of sampling, data collection, analysis, and interpretation (Sandelowski, 2010b). The semi-structured surveys included audio-recordings of the residents' interviews. Field notes that included the researcher's observations of silence, body language, and environmental factors that were pertinent to the interview were recorded during the interviews. It was essential that the researcher remained flexible and sensitive to the social context of which the data was generated.

Methods of Questioning

The questions for this study were *realist* questions that targeted residents' descriptions of things that mattered to them in the context of living in nursing homes. Maxwell (2005) claimed that realist questions generate data that qualitative researchers consider as evidence about the nature of a phenomena that is considered to be real for the participant. Risks that could have occurred with using realist questions included researcher-imposed bias and the potential drawing of inferences that supported incorrect conclusions. To overcome these risks, Maxwell emphasized the importance of addressing potential validity threats that may occur with imposed bias and reactivity which may occur as a result of the researcher's influence on the participant during the interviews. In order to promote validity of the study, I was careful not to lead the residents and remained cognizant of how my presence could have been perceived by the residents. Maxwell implied that performing a qualitative study with restricted questions could create a more serious negative impact of error in the study than invalid conclusions. Asking open-ended questions provided guidance for the residents in describing things that mattered to them while living in nursing homes. It was critical that I continued to be

mindful of my own experiences while working in nursing homes and that the actual data revealed what the residents described matters to them in nursing homes. The residents agreed to a one-hour interview and a follow-up visit lasting approximately one hour to affirm their descriptions of things that matter to them in nursing homes.

Questions for Residents

Newman (1994) discussed creating a space for patients where the focus is on the patients themselves as experts in their care. I used low inference when interpreting the data; therefore, I did not seek for in-depth understanding of the residents' experiences. However, the residents could have increased their level of consciousness if they felt greater inclusiveness in nursing homes when they were encouraged to share things that mattered to them. Conducting the interviews and presenting open-ended questions as I assured confidentiality and honored the residents' chosen location, time, and place in the nursing home were essential for instilling a trusting relationship. Assuring an optimal participant–environment interaction as described by Newman promoted validity in this study.

Researchers who prepare interview questions about a topic prior to the time of the interviews and encourage participants to unreservedly share their responses reveal using a semi-structured interviewing technique (Polit & Beck, 2004). Semi-structured interviews were practical because the purpose of this study was to learn what residents state in their own words as mattering to them while living in nursing homes. Creating open-ended questions prior to the interview addressed the topic of things that matter to the residents. Creswell (2007) suggested creating approximately five open-ended questions when preparing for interviews. The interviews began with a broad, general question presented

to each of the residents: “Would you describe what it is like living here in the nursing home?”

The questions became more directive according to the resident responses and led to specific questions such as:

- What things matter to you while you are living here in the nursing home?
- Can you tell me more about what makes these things matter to you?
- Will you tell me what things that matter to you are included in your care?
- Will you share with me things that matter to you that should be included in your care?
- Will you share with me things that do not matter to you that are included in your care now?

Data Analysis

Content analysis is the most common approach used in qualitative descriptive studies (Sandelowski, 2010a). Sandelowski (2010a) explained that specific to qualitative description, the data is reduced in a manner that keeps the data close to the context, yet moves the data toward a new idea or concept. The detailed information in this study, actual descriptions of things that matter to residents, was targeted in the data analysis. Categories were organized and continually compared to the ongoing generated data and additional clusters, categories, and codes emerged until the data became redundant.

Conventional content analysis described by Hsieh and Shannon (2005) was an optimal approach for data analysis. Conventional content analysis is useful in research methods that permit categories to emerge from the data with a goal to describe phenomena (Hsieh & Shannon, 2005). No preconceived categories were imposed since

the content analysis was grounded in the actual data. Hsieh and Shannon described the data analysis approach using the following steps:

- Use open-ended questions followed up with probing questions that are also open-ended, yet correlate specifically to the residents' conversations.
- Read the data to obtain an overview of the whole data.
- Re-read the data with highlighting words that reflect the studied concepts.
- Create notes of first impressions and the initial analysis.
- Create labels for themes which become the initial coding themes.
- Sort codes into categories that are further organized into broad clusters.
- Re-organize categories into smaller categories.
- Define each of the categories and codes.
- Link relationships among the categories if linking these relationships will support the purpose of the study.
- Read and reread the data with highlighting words that reflect concepts being studied and continue to group codes in into clusters.

Hsieh and Shannon (2005) described advantages and challenges of using conventional content analysis. The main advantage was obtaining direct information grounded in the actual data of what mattered to residents as directly described by the residents. A challenge could have been lack of developing understanding of the context; thereby, neglecting to identify important categories. In an attempt to reduce missing categories that were key to the study, I took the following steps: (a) established rapport and trust with residents so that they felt that they could openly share their thoughts; (b) observed and recorded field notes about the residents' nonverbal behaviors, attitudes,

or periods of silence during the interviews in order to capture the residents' indirect perspectives; and (c) obtained peer debriefing so that perspectives of the data in addition to my own perspectives were included. Another challenge to using conventional content analysis was that it may be confused with other preferred content analysis methods. Research that requires interpretation using higher inference in methods such as phenomenology, extend beyond the approach of conventional content analysis (Sandelowski, 2010a). Sandelowski (2010b) described qualitative description as an approach that keeps the "data near" to the actual data that is parallel with the conventional content analysis that incorporates a grounding of the actual data. This study revealed interpretation of data that Sandelowski considered as "low-inference descriptions" where the data was generated closely to descriptions that the residents shared (2000, p. 335).

Trustworthiness

It is essential to address potential concerns of validity in all aspects of the qualitative research design (Creswell, 2007; Denzin & Lincoln, 2005; Maxwell, 2005; Sandelowski, 1986; Sandelowski & Barroso, 2007). There is no one quantitative or qualitative method that is supreme for gaining knowledge in research (Denzin & Lincoln, 2005). Although qualitative research has been scrutinized for reflecting a lack of criteria that supports methodological rigor, it serves as a superior method that reflects rigor for the purpose of offering new insight in some nursing research studies including this study research. Various frameworks (Creswell, 2007; Denzin & Lincoln, 2005; Lincoln & Guba, 1985; Maxwell, 2005) reflect ways to instill rigor in qualitative research that are in congruence with Sandelowski's assertion that the "essence" of a phenomenon" is the key

to meaningful qualitative research (1993, p. 3). Creswell (2007) iterated the importance of prolonging the engagement with participants and using triangulation that includes peer debriefing and member checking to validate the data. Denzin and Lincoln (2005) also described triangulation and authenticity criteria comprised of: fairness or representing the participant's perspectives; ontological and educative authenticity that acknowledge increased participant awareness; catalytic and tactical authenticities that provide participants with perceptions that they may perform certain actions, such as political or social actions. Ethical relationships and representation of the participants' voices were other distinctive characteristics of criteria that promote validity. Maxwell (2005) discussed the importance of long-term involvement between the researcher and participants, obtaining rich data, participant validation of the findings, and triangulation that includes using different settings during the interviews.

Lincoln and Guba (1985) described trustworthiness as value of the study findings supported by criteria that is meaningful for the research. Sandelowski (1986) expanded on Lincoln and Guba's criteria for understanding rigor in qualitative research specific to human participants. I focused on Lincoln and Guba (1985) and Sandelowski's (1986) following criteria of rigor that enhances trustworthiness for qualitative studies: credibility, fittingness, auditability, and confirmability. These criteria are congruent with the theory of Health as Expanding Consciousness that centers on establishing interconnectedness with persons and expanding their ability to react in a complex environment as a result of person–environment interaction. These criteria reflected meaningfulness of the data that assisted me to maximize validity for this study:

- Creditability is the uncovering of experiences as perceived by participants (Sandelowski, 1986). Credibility occurs when the researcher presents “faithful descriptions” in the data findings that participants who described the information would recognize as their own descriptions (Sandelowski, 1986, p. 30). It is critical that researchers maintain a focus on the goal of the research study rather than allowing the hyper-reflexivity that occurs when the researcher’s self-benefit becomes central to the purpose of the study (Sandelowski & Barroso, 2002). Lincoln and Guba (1985) reported ways that researchers may strengthen credibility of qualitative studies including prolonged engagement where the researcher builds trust and knows the culture, persistent observation that reflects the researcher’s integration of important information in the data findings, and triangulation that embraces an emerging design or different ways of collecting data such as using interview and observation data. I remained careful not to inflict bias because of my experiences as a nurse working in a nursing home. I recorded field notes observing nonverbal behaviors and periods of silence during the interviews.
- Fittingness applies to the participants’ experiences and meanings within the context of their world that is studied. A threat to fittingness could be interviewing the highest-status or most capable members of a group, considered elite bias, according to Sandelowski (1986). One way to overcome this threat is to assess representativeness of the data instead of representativeness of the subjects. Appropriate sampling of no or

mild-cognitive impairment that represented most of the nursing home populations and sampling from the overall long-term care sections of the nursing home was used to minimize elite bias. The residents' validating the findings of things that do and do not matter to them was included in the data. The repeated visits with the residents provided an opportunity for them to confirm validation of the data.

- Auditability occurs when additional researchers find logic in the flow of data collected and concurrence with the interpretation of the research findings. An audit trail provides an organized method to assemble all documentation of each stage of the research process and facilitates maintaining clarity in the flow of the research process (Lincoln & Guba, 1985; Sandelowski & Barroso, 2007). Lincoln and Guba (1985) discussed using peer debriefing as a way to clarify interpretations and keep the data findings honest and accurate. Seeking the input of experts in qualitative research and gerontologic care enhanced auditability for this study.
- Confirmability is meaningfulness of the data findings supported by an engaged researcher–participant relationship. Ways to instill confirmability in the study included establishing rapport and trust with the residents; assessing for any potential Hawthorne effect, described by Maxwell (2005) as reactivity of the participants to the researcher; and revisiting the residents to promote trust in the relationship and to validate the research findings.

Hsieh and Shannon (2005) described the impact of appropriately defining categories and assigning codes to enhance trustworthiness. It was essential to keep in mind that triangulation of the interviews or methods may be necessary as guided by the data (Maxwell, 2005). Observations of residents' conversations were recorded in the field notes. Intra-reliability occurs when that data is analyzed and re-analyzed, and secondary analyses support the initial analysis (Sandelowski, 2010b). Ways to assure intra-reliability include keeping categories parallel and using same semantics according to Sandelowski (2010b). Reviewers from the dissertation committee and I studied the categories and compared interpretations of the data when describing the categories.

Sandelowski (2010b) claimed that researchers must become embodied within the data analysis process. Getting a sense of the whole, pulling out the facts using low inference interpretation, and using ways to systematically organize interview questions and content analysis were essential when beginning the data analysis. A "negotiated" validity is more likely to evolve when research team members make known an understanding of their viewpoints about the findings throughout the research process and integrate these discussions in the audit trail (Sandelowski & Barroso, 2007, p. 230). I obtained assistance from the dissertation committee members for continued feedback during the research process. Making notes and organizing the content in a table were ways that promoted a systematic organization for the data analysis. Including an audit trail comprised of all records of the interviews, transcriptions, coding, and all of the research strategies and activities contributed to transparency and credibility of the study.

Holding bi-weekly meetings via electronic mail or phone conference to share data with members of the research team provided expert review for enhancing validity.

Using a matrix in Microsoft Word and highlighting words in different colors, was helpful in distinguishing categories and codes during the beginning analysis of the study. Creating a mind map to further assist organizing the data assisted with determining clusters of data.

Summary of Methods

Analyzing residents' descriptions of things that matter to them while living in nursing homes provided innovative ideas to expand the state of the science of person-centeredness and improve assessments of satisfaction in nursing homes. It is well known from the literature that person-centered care and satisfaction surveys have improved quality of care in some nursing homes although specific ways to capture what the residents describe themselves matter to them needs further examination. This study captured things that matter to residents that may advance current methods of rendering care and assessing satisfaction for residents who live in nursing homes. Offering new insight about things that matter to residents will address the AACN's (2010c) concern about the need to improve gerontologic care in ways that promote autonomy and non-coercive decision-making for older persons (AACN, 2010a, 2010b).

CHAPTER FOUR. RESULTS

The results are an interpretive integration of descriptions shared by ten residents who participated in the study. A description of the sample is included in the results chapter. The narrative descriptions are grouped into codes within sub-categories, categories, and meaningful clusters. The codes and sub-categories, categories, and clusters are labeled and defined from interpretation of the text. Lastly, key findings are shared to provide guidance for the discussion chapter.

In-depth reading of the transcripts assists researchers in uncovering common threads and differences in addition to identifying what may be missing in the text (Sandelowski, 2010b). The investigator read the transcripts multiple times, word by word, in order to obtain an understanding of the overall interview and to determine descriptive codes for the initial coding scheme. Highlighting words in the text and writing notes based on impressions of the findings revealed residents' significant statements; these statements were recorded in a table. The statements recorded in the table were compared and linked throughout the data collection and analysis process. Additional statements were entered into the table as more interviews were completed and the narratives were compared and analyzed. In order to clarify differing impressions of the text, one of two auditors made suggestions and agreed on follow-up questions that would be shared with the residents during second interviews. Consensus was obtained when there were rare disagreements as the researcher and auditors interpreted the meaning of the residents' words and deciphered initial codes.

Creating a mind map provided structure for organizing the initial codes and identifying code labels that were later sorted into sub-categories and categories. Mind

maps are used to creatively display information by drawing links between topics. Topics that are linked enrich understanding of information and generate new ideas (Buzan & Griffiths, 2013). A presentation of the findings includes exemplary quotes taken from the transcripts to label the sub-categories, categories, and clusters. Definitions of the sub-categories, categories, and clusters were developed from the text to support grounding of the actual data. The author extracted 161 initial codes from 10 initial and follow-up interviews. The codes were linked according to interpretation of the text then sorted into 19 categories and 47 sub-categories that are grouped within four meaningful clusters of data.

Description of Resident Sample

The sample was selected from the long-term care sections of nursing homes. The charge nurses in the long-term care sections were approached and asked for names of residents who would be able to answer questions regarding a nursing research study. A copy of the consent letter for the study signed by the nursing home director of nursing or administrator was presented to the charge nurses. The charge nurses were informed that residents with cognitive impairment could be selected for the study; however, the residents would be required to be cognitively and physically able to carry a conversation and participate in the study for approximately one hour during two separate visits. The charge nurses presented a list of residents whom they stated would be able to talk with me and participate in the study. Residents were selected individually from the lists and invited to participate in the study. If a resident on the list was not available for interview, the next resident's name on the list was selected. During subsequent visits to the nursing

homes, resident names were chosen from the beginning of the list of those residents who were not previously approached about the study.

A description of the study was shared with 14 residents who were selected from the lists provided by the charge nurses. Three of the 14 residents chose not to participate in the study. Another resident, a 92-year-old male, agreed to participate in the study; however, his completed MoCA score of 13 out of 30 revealed cognitive impairment that was not within the range for mild or no cognitive impairment (18–30). The resident was informed that the required score on the MoCA was not met; therefore, he was not eligible to participate in the study according to the study requirements. The resident nodded to affirm that he understood the rationale for the study requirements. Ultimately, there were 10 residents who agreed to participate in the study, met the cognitive assessment requirement, and completed the initial and follow-up visits. Residents’ ages ranged from 79 to 94 ($M = 87.20$; $SD = 5.71$). Length of stay in the nursing home ranged from one month to 13 years ($M = 2.68$; $SD = 3.82$) years. The MoCA scores ranged from 19 to 28, revealing seven residents with mild cognitive impairment and three with no cognitive impairment ($M = 24.20$; $SD = 2.82$). See Table 4 for characteristics of the residents who participated in the study.

Table 4

Characteristics of Residents Participating in the Study

Resident	Sex	Age	Number of Years/Months Resided in Nursing Home	MoCA Scores
1. Grace	Female	84	1 year	22
2. Phyllis	Female	79	1 year	22
3. Joan	Female	98	3 years	26
4. Jenna	Female	87	2 years	19

Table continues

5. Virginia	Female	87	13 years	27
6. Margaret	Female	86	5 months	24
7. Vincent	Male	82	4 years	27
8. Dale	Male	84	1.5 years	23
9. Vivian	Female	94	1 month	24
10. Marilyn	Female	91	10 months	28

Note. MoCA scores of 18–26 = mild cognitive impairment and 27–30 = no cognitive impairment (Nasreddine et al., 2005).

Four of the 10 residents resided in private rooms and six resided in semi-private rooms within the long-term care sections of the three nursing homes. The residents in the semi-private rooms shared a room with one other resident. All but one of the residents was in their rooms when they were approached about participating in the study. One of the residents was seated in the central court of the long-term care section of the nursing home, and she suggested that we return to her room for discussing her participation in the study. During the initial visits, room-mates were present in two of the residents' rooms when the residents were approached about the study. When the two residents were asked if they would like to move to another area within the nursing home, they requested to remain in their rooms to discuss their participation in the study.

The purpose of the study was shared with each resident then each was invited to participate in the study. The requirements for study participation were explained to the residents. These included one approximately 60-minute interview, a follow-up interview (lasting no longer than 60 minutes), and completion of the consent forms and MoCA. The residents were informed that the study was voluntary and their participation or refusal to participate would not affect their relations with the nursing home staff members. They were informed that they could withdraw from the study at any time, take breaks as they desired during the interviews, and could end the interview at any time. The residents were also informed that they could refuse to answer any question presented during the

interviews. Ample time was provided for the residents to ask questions about the study and to read and sign the forms. After signing the forms, the residents completed the MoCA.

I attempted to schedule the first and second interviews within a span of 7 to 14 days in order for both the resident and researcher to easily recollect the discussion of the first visit. Follow-up interviews occurred after 14 days for three of the interviews; however, the residents seemed to recall the initial discussions without difficulty. The delays in follow-up interviews included:

- Twenty-one days between the first and second visit for the fourth resident. The resident was transported from the nursing home to the hospital for admission between the initial and follow-up visit. When visiting the resident to schedule the follow-up visit after she returned from the hospital to the nursing home, the resident was found lying in her bed resting with her eyes closed. Therefore, scheduling the follow-up visit was postponed. During a second attempt to schedule a follow-up visit, the resident was in a physical therapy session as a result of a fall that led to her hospitalization. The resident was in the beauty shop during the third attempt to schedule a second interview. The resident suggested the follow-up interview occur at the time of the fourth visit to schedule the follow-up interview.
- A follow-up visit that was 28 days after the initial visit for the sixth resident. The time required for transcribing the initial interview and receiving auditor feedback led to a date later than agreed upon for the follow-up visit.

- A lapse of 23 days after the initial visit with the tenth participant to assure the residents did not contract a viral syndrome from the researcher.

Subsequent visits were needed for completing interviews with the fourth and ninth residents.

- After 30 minutes into the follow-up interview with the fourth resident, the physical therapist arrived to take her to a physical therapy appointment that she had forgotten was scheduled. Therefore, the follow-up interview was completed after her therapy appointment.
- During the initial interview with the ninth resident, a physical therapist entered the room and asked the resident if she would like to participate in therapy at that time. The resident commented that after having therapy it would be time for lunch; thus, the resident agreed to discontinue the interview and complete the initial interview the next day.

Sub-categories, Categories, and Clusters Identified in the Findings

Overall, the findings revealed that the residents were grateful for being taken care of in the nursing homes; however, they seemed dispirited due to having no choice but to leave their homes and live in the nursing homes. The nursing home became a “second home,” yet it was much different from living at home. Receiving good care occurred for all of the residents, yet all but one of the residents talked about dealing with many challenges during their care. The interviews revealed descriptions of joy, gratitude, and appreciation while living in the nursing homes. On the contrary, sorrow, sadness, and challenge while living in the nursing homes were uncovered in the interviews. Four

clusters and twenty categories related to the residents' descriptions of positive and negative experiences are identified in Table 5

Table 5

Overview of Resident Categories and Clusters

Categories	Clusters
Living in a nice place Being in the right place Making the nursing home like home Making the most of what you have Finding contentment	Accepting life in the nursing home
Necessary losses Losing independence Comparing the nursing home to home Never-ending sorrow	Enduring loss
Having good care Having help when I need it Checking in on you Things are taken care of Feeling presence Appreciating staff	Relishing good care
Getting through difficult times Wanting more information Wishing for things that are impossible	Getting by

Narrative of Residents Findings

Carlsen (1988) iterated the importance of remaining open-minded when attempting to capture the essence of a person's "individual meaning" (p. 72), which she described as things that are most important to a person. Providing ample time, holding the interviews in the areas designated by the residents, interviewing the residents with compassion for understanding things that were important to them, and visiting the residents for second interviews assisted in forming entrusted relationships with the

residents. For the most part, the residents seemed genuine in their responses and eager to share their experiences about living in the nursing home.

The narratives were referenced with resident numbers assigned one to 10 in the order that residents were interviewed. The residents' statements were respectively numbered and inserted after the resident number. A letter or letters were assigned to each code and inserted at the end of the number assigned for each of the residents' statements.

Cluster 1 Accepting Life in the Nursing Home

Residents are more likely to maintain a positive viewpoint when they accept transitioning into a different living situation (Bradshaw, Playford, & Riazi, 2012).

Residents who upheld positive viewpoints when transferring into nursing homes experienced an enhanced resilience that assisted them in maintaining independence.

Bradshaw et al. (2012) also found that residents who maintained positive attitudes were more likely to adapt to living in the nursing homes where they perceived "living well" (p. 43).

The residents talked about the nursing home as the place where they should live because they were unable to care for themselves in their homes. They described things that they could no longer do for themselves, such as walking and performing their daily care. Four of the residents stated they had suffered strokes with residual weakness that led to their needing assistance with ambulation. Two residents who suffered strokes stated they did not ambulate at all. The remaining eight residents claimed that they needed assistance with ambulating. Seven of the 10 residents stated they had repeatedly fallen and five residents expressed a fear of falling. Two of the residents had fractures secondary to their falls, which they stated resulted in their inability to care for themselves

at home. One resident had blindness in one eye as a result of shingles and severe arthritis that led to his inability to care for himself. Two residents had severe arthritis that limited their mobility in using their hands although they could feed themselves and write their name. Another resident described having severe edema and liver failure that led to her admission in the nursing home. Five categories were related to Cluster 1 (See Table 6).

Table 6

Cluster 1: Accepting Life in the Nursing Home

Codes	Sub-categories	Categories
Living in one of the best Nice reputation Being as good as you expect Good food		1.1 Living in a nice place
Family making the decision Having no other choice Wanting family to not be obligated This is where I should be I belong here This is permanent Life goes on	1.2.1 Relieving family from the burden 1.2.2 Accepting that I am here	1.2 Being in the right place
Like a second home Having things from home	1.3.1 Becoming home 1.3.2 They are like family 1.3.3 Having my own things	1.3 Making the nursing home like home
Taking care of myself Things I can do I help myself I want to do it myself I don't ask for things out of the ordinary I'm easy to take care of Being independent I'm kind of free	1.4.1 Keeping active 1.4.2 Remaining independent 1.4.3 Doing what I want to do	1.4 Making the most of what you have

Table continues

I don't complain	1.5.1 Being comfortable	1.5 Finding contentment
I'm satisfied	1.5.2 Having few complaints	
	1.5.3 Being satisfied	

Category 1.1 Living in a nice place. Nine of the 10 residents described living in a nice nursing home. Nursing homes that were considered one of the best and had a nice reputation surfaced in the interviews: “Well, it’s real nice here...it’s a good place. It’s one of the best” (2.002B). “I think this place has a nice reputation” (6.005B). The nursing home was the “next best thing” to living at home and it became “home,” as stated by one resident who made the comment, “I can’t ask for anything better than...than right here. Other than home, but, uh, that’s now here” (1.009B).

Three of the residents revealed lack of having information about other nursing homes and seemed inclined to believe that they lived in the best nursing homes: “I couldn’t find a better place than this is” (3.007B). “You won’t find a nicer, cleaner, place than this is...and you will find problems wherever you go” (3.008B). “You won’t find any that are any better than this....It’s clean. It don’t smell; good food.” On the contrary, she repeatedly stated, “It could be a lot worse” (3.012B), and also stated “I don’t know if it could be any better” (3.013B). Another resident mentioned that her family claimed it was the best place, and she thought it was a good place, too: “They got together and said this is the best place” (5.001B). “I really think it is really a good place” (5.003B). The resident (number 10) stated,

I think that any place...I’m not familiar with any of the other places like this. I’m familiar with this and I love it. If I have to be somewhere, this is fine, but I think most any place, there are people who are loving, caring, and willing to help. (10.146AW)

Having good food in the nursing homes was important to nine of the residents. The food was extra good for one resident who stated, “Good food, extra good food, and desserts are just ultra” (9.004C). “I call in and it comes right there (looks toward the table beside her chair” (9.005C).

One resident commented that her meals were planned according to her needs:

When I get a meal, they do it according to what...to me. They even have sugarless pie for me. And...and all of these things is important because if I'm going to live here, I've got to eat and stay healthy. (4.017C–4.109C)

Having a selection of food was important to several of the residents who stated, “They usually have a choice of two main things, but you can always ask for something else” (6.014C). Another resident made the comment: “Just choose from the menus. Usually get something we like” (2.011C–2.012C).

Other descriptions of things that made the nursing home nice included the residents' view from their rooms, ways the nursing home was managed, and service provided by staff. The residents repeatedly talked about their nice rooms: “The nice setting...big window...sort of live outside...know what goes on” (9.002B). One resident commented, “Don't have to share a bathroom. I've got a good view....I was lucky to get this room” (2.005B). Another resident enjoyed watching staff and other residents in the hall from her room and stated, “I've got the best on third floor” (3.001B).

The way the nursing home was managed appeared to be important to two residents who stated,

The way the place is run is important to me. That's the reason I came here....They have a lot of things going on and I don't have to lay [*sic*] in bed. And that activity girl...you can go over there and ask for anything and you know, they'll give it to you. (4.011B)

All of the residents commented positively about the various activities provided in the nursing homes even though they did not partake in all of the activities. Another resident commented on the overall nursing home and stated, “I’ve learned that if you have to be some place, this here is about as good of place that you can expect to be. I think they treat everybody pretty well” (7.001B).

Decent service for one resident included having assistance when needed: “The nurses...you hail them down if they’re not busy.... ‘Will you take me back to my room?’ (she implied this is what she asks the nurses). ‘Yes’ (implying this is what nurses state in response to her)” (3.010B). According to another resident, “They’re always uh...they’re always kind and friendly and helpful. I repeat that, but that is very important...very important” (10.052K).

Category 1.2 Being in the right place. Nine of the residents expressed that living in the nursing home as the best option for them since they were unable to care for themselves at home. The residents felt they had no choice but to accept living in the nursing home because they did not want to burden their families. They revealed acceptance of their life in the nursing home and inferred they were in the right place in order to please their families.

Subcategory 1.2.1 Relieving family from the burden. One resident repeatedly shared her desire to become no “obligation” to her sons:

I want to be taken care of here...when they come, I want them to want to come or to be good pretenders (she stated jokingly). I really don’t want to be an obligation to the boys. I don’t have any crying sessions and no asking them. I don’t ask them...I do want them to know what’s going on here, when... then they can choose if there’s something going here that they want to see, too...well makes me feel better. (9.114–9.116S)

For two other residents, the nursing home became home when they felt they had no choice because their health regressed and their family members moved away. One of the residents stated, “I know I have to be here. I can’t move to Illinois. This is my home now. I don’t think it will ever change” (4.024D–4.025D). When talking about her family members moving away, she stated, “I’ve got good kids, only they don’t live right here. My daughter-in-law works. My son moved to Illinois and everybody works” (4.077–4.080S). Another description of family living distantly surfaced when the resident stated, “The kids moved around away...and they decided I couldn’t take care of myself. I needed some place they could take care of me and they picked this place” (5.087S–5.088S).

It was important to two of the residents that their children were happy about the nursing homes where they resided. The residents were thankful that their family members chose the nursing home for them. One of the residents stated she was grateful that her sons felt she was in the right place: “I am glad that the boys like it. They think I’m in the right place” (9.106S). Another resident talked positively about the nursing home that she called home although she mentioned a desire to make her kids happy:

This was the place they decided to put me. I have no qualms...my children will do anything that I need. I mean there was no way I could make three kids unhappy because I was unhappy. I don’t know what I would do if I didn’t have my three kids. My sons...my two sons have talked to the people here before I came here...but they said this was the best place. (1.069S–1.077S)

One of the residents referred to her family when she stated, “And I guess they couldn’t depend on me to take care of myself, which I couldn’t because I fell down, so then they shipped me over here to the third floor and I’ve been in here for...I don’t know” (3.122S). Another resident’s family members chose the nursing home for her because it

had a good reputation and they wanted her to be in a place where she would feel comfortable. She commented, “That’s why my kids chose it. It means they’re thinking is on me” (6.059S). An additional resident stated, “There are a lot of places where I could have been. My son and daughter-in-law looked at a lot of places and this is what they chose and I thank them for it” (10.089S).

Subcategory 1.2.2 Accepting that I am here. Nine residents seemed to accept that they would permanently live in the nursing home. An additional resident acknowledged his need to temporarily reside in the nursing home although he repeatedly talked about his goal to return home someday. Another resident stated she was grateful to be in the nursing home although she had no choice:

I think I’ve decided definitely that this is where I belong and it’s right and what else is there to say? I haven’t any choice. At 94, I’m grateful. I recognize this is permanent. I am here permanently and, uh...very satisfied that I am. I feel that this is signed on permanently, so...I’m not fighting it. (9.010–9.015D)

She described what it meant to her to “belong” in the nursing home:

I don’t feel that I should be somewhere else...or have the opportunity to be somewhere else...Completely...completely, uh...sure of that. Well I can’t picture me in my own home and I don’t think I ought to be with a boy. I can be. I’m invited. I don’t think that’s fair to them, and maybe me and the wife wouldn’t get along too well and I definitely should be here...for mine and their betterment. (9.012D)

Acceptance of living in the nursing home seemed to occur for another resident who went “along with it” because his family had no recourse but to have him moved to the nursing home:

My daughter didn’t take that away from me when she sent me to the hospital, and then from the hospital to here, and really....You had nothing to do with it, but then again...using your brain, you would understand that you could not stay at home. I was falling...that’s why she sent me to the hospital. That makes about four or five times I had to call the EMS to get me up off the floor, so nobody took that away from me except my own

body. And unfortunately there's no store you could go to get second-hand parts. I mean, what you've got you have to live with. So you go along with it, because I am not sure I could sit down with a piece of paper and a pen and come up with a better situation. (8.167AW–8.169AW)

For another resident, living in the nursing would be “forever.” The resident stated, “I will be here” (10.139AW). “It's going to be mine forever, I guess. Well, I've come to the conclusion that it's going to be” (10.142AW–10.143AW). One of the residents repeatedly stated, “Just accept it as it is” when she talked about missing things that she used to do since moving into the nursing home. She acquiescently stated that days in the nursing were “the same.” She also stated that each day was “just another day” (3.363AW–3.364AW).

While one of the residents talked about how fortunate she was to live in the nursing home chosen for her by her children, she frequently made a point of having “no regrets” about situations in her life (1.136G). She often stated, “Life goes on” when she talked about various losses while living in the nursing home. She stated, “Those days are over” when she talked about various past life events and things that she could not do in the nursing home such as gardening (1.134G).

Even though another resident acknowledged that he was not able to care for himself at home, he seemed to accept residing in the nursing home temporarily to gain his strength so that he could ambulate again. He continually talked about striving to get better so that he could return home and stated:

My whole goal ever since I came here after my stroke is to get better and be able to walk like a regular person and go home....And I think my wife is going to take that to heart one of these days and get me started...so that will maybe come true one of these days. (7.115G)

He repeatedly made it known that he hoped to return home:

Well, you have to realize that sometimes you just are not able to do some things, like I want to walk and learning how to walk again because I want to go home. And I won't be able to go home unless I am able to do things myself. (7.131AW)

Category 1.3 Making the nursing home like home. Six of the residents commented about the nursing homes that became their “home” or their “second home.” Some residents talked about the nursing home staff and other residents who became their families. The residents’ personal possessions brought into the nursing home from their homes seem to give them pride, ownership, and a closeness to home.

Sub-category 1.3.1 Becoming home. One resident stated, “It’s just home away from home. I’m home. I mean...I’ve got everything I want” (1.015D–1.016D). Another resident compared the nursing home to home because other residents were like neighbors. She stated, “I just call it my home...and I like it. Well, it’s more home...like I’ve got neighbors” (4.022D–4.023D).

Another resident seemed at peace about being in the nursing home when she described what “home” meant to her:

It was a pleasant place, and this is a pleasant place, so I can't really say...In some ways it's different, yes, but there is the pleasantness and so on. I can't disregard that. You can have all of the advantages of a home and plus the care that is needed. That's what home means to all of us, where people care where they are always there and that's what you have here. Whoever made the plans for, uh,...home like this, which is a home for a lot of people....It's going to be mine forever I guess and, um, I think they did a wonderful job. (10.006D–10.009D)

Living at home seemed “long ago” for one of the residents who had lived in an assisted-living section of the campus prior to coming into the long-term care section of

the nursing home. The resident appeared to surpass her thoughts of home when she mentioned that home was “so far away”:

Home was so far away...so gone....I don't feel good enough in home set-up. I don't have those things in mind, the date. Something was '05....I saw in just the last day....I don't know....I can't come up with that. That's a long time ago. (9.006D–9.008D)

Even though one of the residents did not refer to the nursing home as “home,” she stated that the nursing home where she lived was important to her because her mother had previously resided in the same nursing home. She became tearful when she talked about visiting her mother every day when her mother was in the nursing home. In addition, she talked about growing up across the street from the nursing home and also working at the hospital that was next to the nursing home.

Sub-category 1.3.2 They are like family. The meaning of home for another resident was staff and residents who became her second family: “Well, after living in my house....This is my second house, and it's...it's family. Now this is my family” (5.004D). She elaborated on what family meant to her when she stated,

Well, I become....You become attached to certain people...and, uh,...each one is looking out the other so that it's, uh...it's a family....Each other...and the nurses are excellent. I mean you can always go to them for support if you need it. So I mean...it's just like a family. You go to your mother or...to find out what's going on. (5.004D)

A description of “second family” emerged in another interview when the resident shared her thoughts about the staff members:

Well, turn around, and they'll say, “No, you don't need it this week, or yes, you had better. You're going to have company this weekend.” Well, you'd better. I mean, it's just like a second family. Second family means somebody that's as near and dear to you as...as blood relation, but not. I've come to the conclusion that it's going to be and (paused)....These are as near the family as I...friends and family that I've known for years and years. (10.128AI–10.130AI)

Sub-category 1.3.3 Having my own things. The residents commonly talked about their personal possessions such as family pictures and furniture that were brought into the nursing home for them:

I have my own things. People walk in and they say how nice it looks to have your own things and settled, and I think so too. These things came from my home before I was even in the Carlton (looks toward family pictures hanging on the wall). Ray and I...our home, and uh...all of these pieces were...I've got my own setting and some of my own furniture. It's pretty nice...and people walk in and think that it's an unusually nice setting. See...the chest of drawers are mine, the chairs are mine. (9.017D–9.022D)

Not only did personal possessions from home provide the residents with feelings of ownership in the nursing home, but the residents' choosing their own possessions brought from home seemed important to them as exemplified in the following comment: "Like I said, I have my own stuff. Well, I picked out what I wanted. Those are important to me" (1.017D–1.019D). The resident repeatedly mentioned things in room that belonged to her:

And as I said, everything in here belongs to me except the bed and the nightstands. The other furniture all belongs to me...So it's my home. Yes, all that stuff belongs to me (points to two bookshelves with glass figurines). All of these shelves belong to me. (1.083T–1.084T)

Another example of the importance of possessions brought from home for residents surfaced in the following comment:

What I wanted at that time was some books and things brought in, and she wasn't sure. She didn't say, "No, you can't," but she said, "I don't know. I don't know where we would put them." Well, my son and daughter-in-law took care of that. They brought me a little bookcase, uh, similar to that (pointed to the bookshelf positioned on the floor across from her bed). They brought in and showed it to the people and said, "Now can we put this on the wall?" And they told him where and they said, "There's room, so put it in" and so we did, so I had a bookcase there also. (10.010D)

Category 1.4 Making the most of what you have. Residents all talked about their ability to care for themselves. They felt that they required less care than most of the other residents. In addition, they claimed they did not ask for much regarding their care. Remaining independent mattered to the residents as they described their desires to perform as much self-care as possible.

Sub-category 1.4.1 Keeping active. Although the residents acknowledged that they could not care for themselves at home, they implied that they did not require much care in the nursing home. The residents commonly talked about keeping active by taking care of themselves: “I feed myself completely...I write a little bit. I can do that with my left hand...It can help” (3.092O–3.093O). One of the residents stated, “But I can do most things for myself. I do that by myself. I dressed this morning” (10.121W–10.123W).

Another resident talked about things he could do:

I could do certain things. I could get to the bathroom and get out of the bathroom...certain exercises I do with the therapists...I went to church today. I use that one machine up there that’s a stepper...maybe... anywhere from twelve to twenty times. (8.065W–8.066W)

When another resident talked about staff members who cared for her urinary catheter, she stated, “I’m pretty easy to take care of” (2.062N). She also commented, “I don’t call them unless I need them” 2.053L.

Sub-category 1.4.2 Remaining independent. The desire to remain independent as a result of keeping active emerged in the residents’ interviews. The first resident recurrently iterated the importance of doing things for herself:

I can care about myself...well, with the help of that wheelchair. The only time I see them is when I take my medication. (1.052O–1.053O)

I am one of those people that if I can do it myself, I want to do it myself. I’m a person who likes to take care of myself. (1.060O–1.061O)

They don't do anything for me...unless I ask them for it. (1.120AY)

Another resident felt good about taking care of herself. She felt "in charge" of herself:

Where with me, they know that I'm okay and I can think for myself. Nobody's going to take care of you if you don't take care of yourself, so I mean, you have to learn. It helped me...the word search...and exercise...anything to help myself. It's all about being independent. I want to do it myself. I feel good, which makes me feel good...and I'm satisfied that I'm doing something all day instead of sitting and watching TV all day...so I think I help myself. When I can help myself and they know it, and they let me know that they appreciate it...that I'm helping myself....You've got to. (5.059N-5.065N)

She also stated, "I became in charge of myself...I'm satisfied with myself. Well, I have no problems. I take care of myself" (5.067-5.068O).

For another resident, having control included informing the staff when he needed assistance: "I think the everyday routine...I can more or less have control over that myself" (7.042O). When asked what control over himself meant to him, he replied:

I...I try to let them know...now it's time to put my socks on and my shoes on and get up and go to the bathroom. I can do a little more than I do. That's nice that in the evening I can ask one of the nurse's aides if I can have a cup of ice cream or a snack. Being able to do that is kind of good...a good thing. (7.042O)

In addition, a resident stated that she would not ask staff to push her in the wheelchair because "it's about being independent...[she wants] to do it [her]self" (4.057O). She seemed driven to work hard in therapy that was ordered for her after she had fallen and trusted staff members in "where they wanted" her to be for improving her status:

Of course I'm not a sick person...I'm a worker...working my legs or arms like that. Oh yea, because I worked hard...I worked hard to be where they wanted me to be. I was on the machine and I had to pump and use my arms at the same time and I had to do so many of them. So every day I improved. (4.052N-4.054N)

Although the residents preferred to care for themselves, sometimes they hesitated to bother staff. One resident stated, “I just say, ‘Do as you can. I don’t want to take you from other people.’ I always say, ‘You’ve got other people to take care of’” (6.041L–6.042L). Reluctance in bothering staff was uncovered in another interview when the resident stated, “Then I’ve got to bother somebody...turn my light on. Why bother them....They’ve got work to be done. I mean, I don’t ask for much except to get up and go to the bathroom” (3.081L–3.082L). She also stated, “I mean, I don’t ask for much. I don’t ask for anything...anything out of the ordinary” (3.088N–3.089N).

The following comment emerged in another interview:

Uh, I just hesitate...I hate...I’ll wait until I can’t stand it anymore before I’ll ring for anybody during the night because even though they’re on duty at that time, maybe they’re tired, too, so I don’t want to them running unless I absolutely have to have it. (10.077L)

On the contrary, one resident did not want to be bothered by staff and she repeatedly stated, “Well, they know I don’t need anything...don’t need any help” (1.056N). “They don’t bother me. Thank God they’re not in and out of here all the time. I’m glad they leave me alone” (1.036K).

Sub-category 1.4.3 Doing what I want to do. Four of the residents expressed the importance of doing what they wanted to do while living in the nursing homes. One resident stated, “I’m just kind of free. I can do whatever I want to. They let me live my life” (1.057O–1.059O). It was important for two residents to choose any place in the nursing home where they desired to go. One resident talked about visiting another resident and stated, “I can go visit when I want” (2.063O). Another resident also talked about going anywhere in the nursing home and stated, “I can go anywhere. I didn’t have to get permission or nothing” (4.055O). When asked what it was like to go anywhere in

the nursing home, she stated, “Like this is my home...and it is” (4.055O). She also made the comment, “Yea, if I want to do that” when she referred to staying up late (4.056O).

Category 1.5 Finding contentment. Comments about the nursing homes being nice and clean, having good food and decent service, and providing various activities seemed to make the nursing homes nice places to live for the residents. Furthermore, five of the residents elaborated on being comfortable, having no complaints, and overall being satisfied with the nursing homes, which seemed to provide some level of contentment for them.

Sub-category 1.5.1 Being comfortable. One resident stated, “Well, I am comfortable here temperature-wise, and uh, I can have help any time I want it. It’s comfortable as far as I’m concerned. I don’t know of anyone who has complained, but uh...the beds are good” (9.055I–9.057I). Another resident appreciated “having it nice and warm” in the nursing home (6.006B).

Sub-category 1.5.2 Having few complaints. Six of the residents seemed disinclined to complain about events in the nursing home. One resident repeatedly insisted she had no complaints and stated, “I can’t complain about anything. It’s a nice place. I have no qualms” (1.101AC–1.103AC). Another resident commented, “I ate the blueberry pancake because it was good and I don’t complain....There’s other things I like better” (10.119AC). “There are things I suppose that could be a little different, but I really can’t think of anything right now. They give the time that they have....Every one of them. No, I cannot think of something at all” (10.120AC).

Even though a fifth resident commented, “I don’t have many complaints. It could always be worse” (3.279AC–3.280AC), she frequently mentioned her “biggest

complaint” of waiting on the call light: “The biggest thing that I could complain about is the...the light. That’s the biggest thing that I have to complain about” (3.281AC).

Another resident stated, “And, uh...and just generally, I think, uh...well, I don’t have any complaints” (6.095AC). When another resident talked about having good care, she stated, “I have no complaints” (9.133AC). Further into the interview, she stated, “And good care...and...well understood, and no complaints” (9.134AC).

Sub-category 1.5.3 Being satisfied. One resident was satisfied that she would remain permanently in the nursing home. She made the comment, “Well, it’s kind of good...moved around from place to place several times and, uh...I’ve got my own setting (9.016D). She also stated, “I think I am very permanent...very satisfied that I am” (9.199AT). When she described her inability to prepare meals and dress herself, she stated, “Definitely. I don’t know if there is anything more to say along that line or not, but...(clears throat)...I think I am very content” (9.105S).

Another resident made the comment, “Well, I think that they do everything they’re supposed to do. They do everything that needs to be done for me, and that means I’m very satisfied with [her nursing home]” (6.131AT). For another resident, finding contentment was uncovered in her statement about making the nursing home pleasant: “It is pleasant if you make it so. It’s going to be a good place” (10.144AW–10.149AW).

Having the best room in the unit seemed to provide satisfaction for one of the residents. She repeatedly talked about how she had the “best room” on the floor and she smiled during her conversation about how she watched people in the hall from her room: “I love to watch people, and I just love to sit right here in this chair” (3.172Y). She

further stated, “I’d rather sit here and watch the folks...watch television...I have lots of company” (3.177Y).

Cluster 2. Enduring Loss

The residents described various losses and expressed recurrent sadness secondary to significant loss that occurs in chronic sorrow as described by Eakes, Burke, and Hainsworth (1998). Although they considered themselves having better health than most other residents in the nursing homes, they acknowledged their loss of ability to care for themselves. They had to let go of living in their homes and move on with their life in the nursing homes. Loss of independence as a result of their inability to care for themselves was an example of necessary losses, or losses beyond a person’s control (Voorst, 1986), that surfaced during the interviews. Other necessary losses included the residents’ family members and friends who died. The residents missed doing things they used to do at home. In addition to necessary losses, the residents lost important personal items that were “just gone” while living in the nursing home. They talked about their desires to be at home with their families. In addition, living with other residents who required intense care in the nursing home may have led to disparity about their own health regression. Four categories were identified in Cluster 2 (See Table 7).

Table 7

Cluster 2: Enduring Loss

Codes	Sub-categories	Categories
Losing abilities Feeling helpless Losing spouses and children Losing others in the nursing home Dying in the nursing home	2.1.1 Being unable to take care of myself 2.1.2 Feeling helpless 2.1.3 Wondering what will happen 2.1.4 Losing family 2.1.5 Losing friends 2.1.6 Thoughts of dying	2.1 Necessary losses
Being unable to do things used to do	2.2.1 Transitioning into the nursing home 2.2.2 Missing things I used to do 2.2.3 Loss of control	2.2 Losing independence
It's not like home Getting used to bedtime schedules Comparing to a hospital Leaving go of things that are gone	2.3.1 Living in the nursing home is different from home 2.3.2 Making adjustments 2.3.3 Going to bed and getting up are different here 2.3.4 Comparing the nursing home to a hospital 2.3.5 Losing personal items	2.3 Comparing the nursing home to home
Being with family Missing home Feeling sadness Reaching out to help others Staying away	2.4.1 Longing to be with family and at home 2.4.2 Having compassion for others 2.4.3 Keeping distance 2.4.4 Reaching out to others 2.4.5 Longing for things that are not there	2.4 Never-ending sorrow

Category 2.1 Necessary losses. The residents reflected on necessary losses that inevitably occur in life such as loss of health, death, and events that are not within the

person's control (Voorst, 1986). All of the residents talked about their inability to care for themselves as the reason they required nursing home care. Even though the residents set themselves apart from most of the other residents in the nursing homes because they perceived their level of care as not as intense, they talked about things they were unable to do to care for themselves. Two residents stated they felt helpless. Given the average age of 87, it was not surprising that the residents had lost their own family members in addition to losing new friends they had made while in the nursing homes. Five residents talked about their own dying.

Sub-category 2.1.1 Being unable to take care of myself. Each of the residents required assistance with ambulation and transfers. Seven residents had fallen repeatedly prior to coming into the nursing home. The residents acknowledged their inability and seemed compliant in preventing falls. After one of the residents fell three times at home, her family decided that it was time for her to come to the nursing home. She frequently talked about her inability to do things secondary to discomfort and stated:

Some days I'm better than others, but it's a chore. My arms and legs are just crampy...moving...it's a chore. Sometimes I can't move them at all. Well, I have legs, but they're just no good. I can't stand up. I'm in a wheelchair all the time.

I had good use of my hands, and I use to make....I could sit down and sew quilts and cut material. I can't do none of that now. I don't do anything... just sleep and eat. Don't do nothing....I mean I don't do anything here because I can't walk. (3.146V-3.153V)

The resident was unable to ambulate; therefore, she was transferred by wheelchair. She was unable to propel the wheelchair to see her items in the closet:

I can't walk. I would love to go to that closet (points to her closet near the entrance of the room) and see what's in that closet, but I can't get there.

Once I get in that wheelchair, well, I can't get in that wheelchair, I have to have somebody support me to get in there. (3.153V–3.158V)

The resident's recognition of limitations in self-care surfaced in another interview when she stated:

Some of the things I know I can't do. They always give you a shower. I'm not allowed to do that myself. I used to walk. Can't do that. I can't get up and get around like it used to be. (6.061V–6.064V)

One resident reflected on using a walker:

At first, they said those are too unstable that I probably not be able to use one of them right away...and people have fallen with those....They really emphasize that I should like....get up and use this walker. They walk behind me with the wheelchair. (7.062V–7.064V)

Five of the seven residents who had a history of falling were fearful of falling again. One resident stated:

My legs wouldn't work right. I'm afraid of getting up and falling, and so I keep the door open as much as possible so in case I need help because I have something going on in my mind that I think I'm going to fall. I've done enough falling. (1.031H)

The constant fear of falling surfaced in another interview when the resident stated, "I don't relax unless I go to bed" (2.025H). She talked about other residents attending outside trips to restaurants, but she could not go because of her "balance" problem.

In addition to recurrent falls, five residents had difficulty using their hands. One resident selected foods that she could handle most easily. She refused foods that she would enjoy eating at the nursing home, such as the ribs and spaghetti, because they were too difficult for her to handle. She stated, "Yea. I don't have control over my hands and then I sometimes drop it, so I make a mess. We wear a bib [*sic*] and it helps" (2.099V).

The increasing difficulty for another resident to use her extremities surfaced in one of the interviews:

I can't even get that out anymore (appears to be unable to extend her index finger). This hand is just plain numb. I can't get up and walk out to see....I can't move because I have no legs....They're there....They just don't move! (3.165V–3.171V)

Arthritis caused another resident to require assistance with dressing. She stated, "I can't do it. I have to get somebody to dress me because my hands won't work" (5.108V).

In addition, a resident mentioned tremors in her hands when she talked about her desire to join the activities in the nursing home, "Now with my tremors, I can't do it" (4.100V).

She further commented,

I mean the older you get, you need help. You really do. Most of the time I get through with my legs. I still can't walk. I still can't walk. They put that thing around me, but I still can't walk very far. I get *charlie horses* and they hurt, and they stay that way a couple of days. (4.092V–4.095V)

Various problems led to another resident's admission into the nursing home when he described what it was like to have health issues:

And then I was having hallucinations...I would swear that, uh, I was in my own house. "No you weren't." "Don't tell me where I was at. I know that house." "Either they're trying to drive me nuts or I'm going nuts!" My eyes are burgered [*sic*], too...uh...I think that's one of those floaters. Well, the first thing that got me was the rheumatoid arthritis, and I'll tell you, anybody that's had it knows what it's like. Uh...it's not just plain old uh...arthritis. It does things to your limbs. Your fingers get all conbobulated [*sic*]...they're turned down like that for the rest of my life....Your toes go the wrong way, and you have to have them operated on...uh, that's the first thing. Then the second thing that, uh,...the body took from you, in my case, I think was the uh...uh the shingles getting in that eye and taking that eye. And then, I don't know, maybe it's old age, I don't know, but the falling down when you've got no reason to fall down was another thing. You know, boom...it's gone. (8.123V–8.124V)

Throughout the interview, he repeatedly talked about being unable to care for himself:

I was falling...that's why she sent me to the hospital. That makes about four or five times I had to call the EMS to get me up off the floor, so nobody took that away from me except my own body. And unfortunately there's no store you could go to get second-hand parts. I mean, what you've got you have to live with. (8.168AW)

Sub-category 2.1.2 Feeling helpless. Two of the residents mentioned feelings of helplessness. One resident made the following comment about what helpless meant to her when she stated, “When you can’t do your shoelaces or open a safety pin or do things with this hand (looks at her left hand), that’s helpless” (9.114V). She repeatedly mentioned feeling helpless:

I can’t get my own meals, and I feel that I need the nurse or whoever it is to get me up and dressed and undressed and to bed. I just feel that I am that helpless now. I cannot get a meal. I cannot...I couldn’t put on an ankle sock if I had to. I couldn’t open a safety pin. I’m improving those things some and this is still pretty helpless (holds up left arm). (9.111V–9.113V)

Another resident shared her feelings of helplessness:

There are times when there’s nothing except prayer that you can do. And uh, I know there are people that say, “Well you ought to be able to do something.” No, sometimes we’re helpless. With this swelling, I can’t walk. I think, here I am at my age and I have to be...I suppose if they’d let me, I would try it on my own, but I have to pushed into dinner and lunch and breakfast and so on. (10.099V–10.101V)

Sub-category 2.1.3 Wondering what will happen. Three residents seemed to wonder what may transpire for them if their health regresses. One resident stated, “I’ve got some problems, but so far, knock on wood, I don’t have that, but who knows what could happen tomorrow? Today I am 92, so what would happen tomorrow?” (10.093U). Another resident seemed concerned about what type of facility she would live in if she became more helpless. She stated, “I don’t know where I would be as I get more helpless...hospital? I don’t know whether there’s a move between here and the hospital (9.114V). An additional resident alleged that his unstable spine could fracture “any time” and could end his life. He stated, “And that’s not fun to be...It’s not fun knowing that any time, you can twist the wrong way and kill yourself” (8.062P).

Sub-category 2.1.4 Losing family. Eight of the residents' spouses died prior to the residents coming into the nursing homes. The residents reminisced about good times they had with their spouses. One resident stated,

He was the loveliest husband you can imagine...I can imagine (voice lowered). He was perfect for me...in my eyes. And that's his Navy picture up there. I'm proud. I've got Ray's picture in his naval uniform recently, and uh...it's been fun introducing him (chuckled). He's 26 years old and actually I'm six days older than he is (chuckled). It has been a beautiful marriage. (9.040G–9.044G)

Another resident repeatedly stated, "life goes on" when she talked about losing her husband: "But he had heart trouble, so...but anyway...life goes on. I have no regrets. We had a wonderful marriage" (1.135G–1.136G). For another resident, it was best that her spouse did not have to continue living when he was so sick: "We just lost him last summer, but he was too sick to go on. It was best. We had been together 63 years" (6.021G–6.022G).

Losing siblings surfaced in three of the interviews. One resident stated,

Um, my brother who was the closest to me died the first part of December. He was the last...I am the last of the family. He was the last...I am the last of the family, and I think about that a lot and when the sky looks like Arizona and Nevada, I think of my son in Nevada and my two brothers who lived in Arizona who are gone. I think about my parents and what they taught us and I think about relatives who are gone...aunts, uncles, and so on, but I keep telling myself, well, one of these days. I don't feel down anymore, I just feel like I'm here, and when the day comes, I won't be here, but that's alright, I was, and maybe somebody will remember me, I don't know. But whether they do or not I remember a lot of people so. (10.032G)

Another resident talked about losing her siblings prior to coming into the nursing home. One of the residents became tearful when he stated, "I'm preparing myself to losing another sister" (7.104AI). He was also tearful about when he talked about his grandson's death.

Considering the residents' average age of 87, it was not surprising that loss of their own children emerged in the interviews. One resident talked about her daughter who died after she moved into the nursing home. The resident stated, "And the kids all call...You know they use to call and....Now the oldest girl, which just passed away, but...she use to come" (5.090S). She also shared pictures of her father, another daughter, granddaughters, and four sisters. She stated, "I had a nice life" (5.236G).

Another resident made the following comments:

So I was up here and here I am in this room and it's all I've got now. I've got three grandkids. I had two kids and they're both gone; my husband's gone, and I've got the most wonderful niece I could ever have...and two other nieces that take good care of me and....I have no complaints about them. Other than that, one niece was in this morning and uh...I'm hanging in there. (3.369G)

Death was not the only cause for residents to be apart from their loved ones. The inability for one resident to see his wife who lived at home repeatedly surfaced in the interview. The resident talked about missing his wife when she did not make her routine visits into the nursing home:

Tomorrow my wife should show up here about 9:30 or so because we should be going to church....and if she doesn't feel...or we get a bad storm or something...she hates to drive on ice or snow and that would be an unhappy thing if she couldn't be here. (7.057S).

Another resident described his wife's transfer prior to his own admission into the nursing home. Even though she resided in the same nursing home, he seemed challenged in getting to the other side of the nursing home to visit her when he stated, "Yea, I can't even go down and visit the wife unless I can get somebody to grab the belt and walk me down there" (8.022G).

Two other residents talked about missing visits to their home because their family members were not comfortable with transferring and ambulating them outside of the nursing home.

Sub-category 2.1.5 Losing friends. Four residents shared what it was like for them to observe their friends die in the nursing home. One of the residents stated she expected residents to die in the nursing home:

Yes, down this aisle...but she was real sweet. But she had been here for years. Her husband died here. They said he was a wonderful man, too. Oh well, it's something you can't....you expect it in a place like this. But Marge had been happy, and she went on until she got heart problems. She went pretty fast...but life goes on. (1.033G)

Another resident talked about how she became “attached to certain people” (5.004D). She stated, “I used to play euchre. We had a regular group...and then a lot of them have passed away...and I wasn't doing that anymore” (5.158AI).

Another resident became tearful when he talked about losing two close friends in the nursing home:

I lost two friends. Well, it's not nearly like if you lose a member of your family. I knew him pretty well then. His wife even made up kind of a history book. It had pictures and everything. Well, the death of Larry Richards (another resident) was hard for me. (7.102AI–7.107AI)

Insight about what it was like for one resident to share a room with other residents who died emerged in one interview:

I had two of them who were in bed like a vegetable and they tried to talk and you couldn't understand them. I think both of them had Parkinson's disease and both of them died...one in the room and one at the hospital. I've been in here one day and they hauled him away (pointed to the resident in the other section of the room). And I'm almost sure I heard the nurse say there's uh blood oxygen...is seven. And I said to myself, they better get here fast because he's going to go, so I don't know, but that will be three. (8.018G)

Sub-category 2.1.6 Thoughts about dying. Five of the residents shared thoughts about their own dying. One of the residents talked about how grateful she was to have lived longer than predicted by her family when she was admitted into the nursing home: “I found that my son and daughter thought when I came here...four months, that was it. They had been told...four months...that was last September. I passed that mark” (10.140AW–10.141AW).

Another resident shared his thoughts about “ending it” when he stated:

All they have to do is take the box down and throw it in the barrel...and yea, there were times when I was very, very certain that the best thing to do was just to end it. Yea. Uh...to me unless you have quality of life, you’re not living and you certainly don’t have quality of life in here. (8.017G)

The resident further discussed dying during the interview:

But you put it in the back of your mind and say, “I’ll fall some day and get it over with. Is this the one?” And like I say, I have no fear of it. You don’t like it, you’re not going to like it, but uh...to keep on going like this. You talked about committing suicide...and I think I told you that, and uh, yea, I’d be lying if I said I never thought of it because you do think about it. You hurt all of the time you know, you can’t walk without somebody holding your hand...well, in this case, it’s a belt...yea, I can’t even go down and visit the wife unless I can get somebody to grab the belt and walk me down there. Yea, you’ve got to get that through your head and uh...you’ve got to realize, I think, that the only thing you’re going to do is you’re going to die. And, uh...if you think you’re going to get out of that, you’re fooling yourself very much. And how you’re going to die? You don’t know. I don’t like it, but I’m not uh...ending my life just because I have the pain and things that I’ve been going through for 40 years...So I’ll make until it goes naturally. And when it comes, am I going to hide my head under the pillow? No, I’ll tell you I will welcome it, but I’m not going to do it myself. That’s cheating. (8.019G–8.037G)

A resident implied that she expected to die in the nursing home when she stated, “It’s probably where I will die” (1.028G). Another resident shared a positive notion about dying:

I think that will be a great day (smiles)...Don't you...feel that way? I'm ready to die. I've got two kids up there waiting on me (smiles). They're standing right at that gate. They're getting older, too. You know it makes me think that when I die...See, my dad died when I was three. Do you think he will know me now? Is he really going to know me? People know that I'm his daughter...You can't answer that, but I ask. (4.026G)

On the contrary, a resident was tearful when he talked about the possibility of dying in the nursing home:

I told my son, I says [*sic*], "John, I don't want to die at Carlington's Place" (fictitious name of nursing home). I don't want to die here. I've already lost quite a few friends...people I know quite well. They passed while they were living here. (7.015G)

He further elaborated on the meaning of spending his last days at home:

That there means a great deal (becomes tearful; silence). That's where I'd like to spend my last days...sitting on the porch just looking out over the water (tearful). That would be very pleasant for me to spend my last living days up there (silence). (7.117G)

Category 2.2 Losing independence. Losing independence began with the transition into the nursing home for three of the residents who appeared to detach themselves from the sale of their possessions. Six of the residents talked about losing independence since they moved into the nursing home although they mentioned being free to do what they wanted to do in the nursing homes. Loss of independence occurred secondarily to the residents' inability to do things they used to do at home and their dependence on others.

Sub-category 2.2.1 Transitioning into the nursing home. Although nine of the residents described accepting the nursing homes as the place they would continue to live, three residents seemed to detach themselves from the process of selling their possessions when moving into the nursing homes. Even though one of the residents was proud of the

nursing home that had become “home,” she was disgusted because of the way she was moved into the nursing home:

When they moved me...everything was moved for me. They cleaned out my house...and uh...some of my clothes went to the Goodwill. I had to forget a lot of stuff because my kids moved me out of my apartment and I wasn't there. I was here in the room. Disgusting! That's terrible! You know you've got this and you know you've got that and....They're gone! She put a lot of nice stuff in the Goodwill...which... I didn't like...but I had to forget it. (4.074S–4.076S)

Two other residents seemed to separate themselves from the context of selling their personal possessions when they came into the nursing homes. They mentioned their families having an auction. One resident stated, “I had everything turned over to my kids. The boys had an auction and sold everything” (1.08–1.082S). She stated, “I don't own a thing” (1.085T). Another resident talked about her family having an auction when she was in the hospital:

I had a house and a big yard and we had an auction. I had a colostomy the same day I had the auction...I had trouble...blood was coming from my bowels and rectum so I had to go to the doctor and they said I had to have a colostomy. I was 96 years old then...too doggone old and...and I went to a second doctor and he told me the same thing, so I had surgery and I was in the hospital when they had the auction. My house, my car...at 96, I was still driving my car. I never had any accidents. (3.123S)

Sub-category 2.2.2 Missing things I used to do. The residents missed various hobbies and daily activities they did at home. One resident repeatedly talked about missing her garden when she stated, “I loved to work outdoors...Those days are over. That's what I miss any more is my garden” (1.137G); “I love gardening, but it's something you do once in your lifetime” (1.138AW). Another resident stated, “I don't do anything...just sleep and eat. Sleep and eat and watch the people” (3.153–3.154V). She proceeded to talk about how she could longer sew quilts:

I had good use of my hands and I use to make, that's been probably five years ago, I could sit down and sew quilt blocks and cut material. I can't do none of that now. Not much of anything with this one (holds up right hand again). They're numb (referring to her hands). Look at that finger... You couldn't sew with that thing. Not much of anything with this one. (3.166V-3.169V)

One resident revealed a fond memory of doing things she used to do: "Oh no...Some of the things I know I can't do. I used to like to cook. I used to like to bake...and uh...I can't do those things anymore. I can remember about it" (smiles) (6.136P). The challenge of doing jigsaw puzzles led one resident to give them up in the nursing home. She stated, "I always did jigsaw puzzles and I can't do that anymore because of Elsie...she's taking those pieces and putting them back in the box" (5.106V-5.107V). Although one of the residents described tremors in her hands that prevented her from doing activities, she stated, "I was a knitter...I want to learn to do that again" (4.231P).

The residents talked about missing other tasks they used to do at home. One resident considered these tasks as privileges that were "gone":

I always made out my bills...don't do that anymore. Uh...I went to the grocery store, and seems really odd because most people don't like to go to the grocery store, but I miss it! You know, you got in our car, you went to the grocery and you had a list. You want a hot dog...you jumped in the car and you went to the hot dog place and got yourself four or five hot dogs...You got them, went home, and you ate them and Duke could be right beside you waiting his turn and dang it, you miss that stuff! You wonder why you miss that stuff. It's just one more thing that you lost...you lost control. I don't have a car anymore that I can go out and jump in. Oh yea...I'll go get me three or four hot dogs, you know...No you won't because you can't drive any longer and your car is gone. You're not going to call a cab are you...Noooo. I don't know if you can understand that or not...it's just something that you can't do anymore and it's uh...I don't know...you could really call it a privilege. It's a privilege that's gone. You miss going to the drug store...of all places you know. But I think the grocery store more than anything because you're looking at television...well, I never saw that in the grocery store. Now you can't go to the grocery store and it makes you mad. (8.054P-8.057P)

He described lack of independence in having his own money for outings while living in the nursing home:

It's strictly yours you know...or was yours. You can't expect them to say uh...."Well we'll load up the van and take you to the grocery store." Well other than the fact that I haven't any money because somebody else is writing my checks, well, just cancel that because I don't think I can go. It makes you...you get to thinking about it and you think why in the hell am I here, to be honest. (10.058P-10.059P)

Missing other common tasks that were routine at home for another resident emerged in the interview. She missed everything about being at home including doing as she "pleased" (3.093P). She described missing things she could no longer do:

When you're home, drive your car where you want to go. Go to bed when you want to. But you talk about independent...you could stay up as long as you like. You could here, too, but... I was still driving my car. I'd go to church, grocery store, went to the bank. And...independence....You had what you wanted to eat. (3.094P-3.101P)

The residents missed various activities provided by the nursing home as well. Because of balance problems, one of the residents described rarely leaving her room. She talked about staff members providing activities such as therapy, hair appointments, and church services that she viewed on television, in her room. She became tearful when her sister, who was present during the second interview, described the challenge of taking her out of the nursing home because of the difficulty transferring her. The resident also talked about lack of attending some of the activities such as the Residents Council although this was something that she was hoping to do.

Another resident missed weekly visits outside of the nursing home since his health declined. He talked about how he missed doing his "own thing," which was quality of life for him:

When the weather was good, I got out every...almost every Tuesday or Wednesday, and then on the way back, I would usually stop at Wendy's and get those...oh, uh...I don't want to call them "mini," because I don't think that's the name of them, but it's the small cheeseburger and the small chocolate drink and uh...a small chili. And then I didn't have to eat there, but came in the room and ate here...and that is doing your own thing. Quality of life is doing your own thing when you want to do it. (8.061P)

Sub-category 2.2.3 Loss of control. Loss of control emerged in three interviews.

The most important loss of control for one resident occurred when she was had no choice but to depend on others. She stated, "And, (pause) independence, *it* (emphasized, as she stated "it") means so much."

The worst part for her was "having to depend on somebody else." She repeatedly talked about staff "telling her" to do certain things in the nursing home:

Depend on someone when you want to go somewhere....You can't get out and shop like you used to. Buy chocolate candy, and cook like when you was home and (silence)....They tell you what you're supposed to do. They tell you that you have to drink a glass of water after each meal, and I don't like water. You do it because it's good for you. (3.105P-3.109P)

Although the resident agreed that nursing staff members' instruction to drink water actually improved her health, she implied lack of control in choosing what she wanted to drink. When asked if nursing staff members knew that she preferred juice over water, she replied:

I don't imagine it makes any difference. They tell you to drink water because it's good for you...And it is good for you. I said, "Why can't I just drink some juice. It's got a taste to it. Water don't have no taste." But, uh, I drink it anyway. (3.110P-3.111P)

Another resident stated, "To me it's like, uh...you're warehoused. Stick you on a shelf. You might as well be boxed up in a case and put on a shelf...And that ain't [*sic*] right" (8.046P). He also stated, "Same thing you've got here....Do as I say, not what I do....Do as I say. And you do what you're told...if you want to get by" (8.046P). He

talked about having no control in the nursing home: “You have no control over your own affairs in here. If the pill is supposed to be taken at noon...say...then why don’t you give it at noon? It don’t make sense to me. You have no control over anything” (8.061P–8.062P).

Getting undressed in front of staff revealed loss of control for one resident who stated, “It’s terrible the first time you have to take a bath and take all of your clothes off. You’re not use to doing that” (4.059P). She also talked about being restricted in where she could ambulate in the nursing home after her fall when she stated, “Anywhere in here....At that time when I talked to you, I wasn’t restricted. I didn’t have to get permission or nothing” (4.061P–4.062P).

Category 2.3. Comparing the nursing home to home. In addition to the residents missing things they used to do and feeling a loss of control, living in the nursing home was different because of various other changes for six of the residents. Although the nursing home was a nice place, it was not as good as living at home for the residents. Adjusting to the routine of care in the nursing home and losing personal items were uncovered in the interviews. Three of the residents felt it would be impossible for changes to occur in the nursing home to make it more like their home.

Sub-category 2.3.1 Living in the nursing home is different from home. For one resident, “It’s just different...just different than home” (3.028E). When asked about things that were different compared to living at home, she replied, “Altogether different than at home I’ll tell you” (3.020E). Later during the interview she talked about differences of living in the nursing home compared to home: “Doing as you please. Here (chuckles), you don’t any more than sit down at the breakfast table and here comes the

nurse with the pills, and you take those pills and...(silence)....They tell you what you're supposed to do" (3.111–3.113P). Additional things that were different for her at home compared to the nursing home surfaced in the interview:

When you was [*sic*] at home, you had to work, had to clean your house, cook the meals. If you wanted to go someplace, you would get in the car and go. I had good use of my hands and I used to make...that's been probably five years ago, I could sit down and sew quilt blocks and cut material. I can't do none of that now. (3.194E)

Even though one resident claimed that the nursing home was not like home, she purported that the nursing home was the "next best thing!" and "It's as near as you get" (1.006B–1.007B). Another resident implied that no place would be like home when he stated, "It's not as good as home. Nothing is as good as home" (7.007E–7.008E).

One resident found the nursing home to be different than she expected: "It's different than what I ever expected to be happening. I, um...it's not like you say home, and so this is not home, but in word, it is, too" (10.011E). She talked about the different physical environment in the nursing home:

I had two rooms and a bathroom that were mine. As I said, I had five hundred books....And look out the window and I could see much more than I can see here...birdhouses and fields and I could watch some planting and harvesting. The front yard, um...where I face the front yard of our home there, and my son had flowers planted in there where he's going to place a flag pole eventually. I don't know; it was just more open because I could see more. Here, I just go down the hall, so that's a little different, too, and uh...I had more friends come to visit me there than here. I was in correspondence by mail with more people than I am here. (10.012E–10.015E)

She proceeded to talk about the difference in her dining experience:

It's a little different in, uh...going out to the dining area for my meals. There's a dining area here, but there it was Dennis and Doris and myself and the rest of the family sometimes, and I miss that. You can walk around from room to room and look out. Here I can walk from room to room, but it's quite a distance. It's not a complaint. That's just the way it is. (10.019E–10.020E)

Even though the food was “almost like home-cooking” (10.004C), it was not the same as food at home for two of the residents: “The only way to have good German-chocolate cake is make it yourself. It is so good” (stated in whispering voice). She described deviled eggs in the nursing home when she stated, “They’re nothing compared to what they have at home...the ones you make at home yourself...at least they’re deviled eggs” (3.027E). Another resident described the food cooked differently in the nursing home compared to home: “Going back to their food, there’s plenty of it. I can order anything I want, but the heck of it is, they destroyed half of it” (8.004C).

Another resident found benefits as a result of living in the nursing home: “If you were home, you probably wouldn’t go to exercise....You’d have to go to the store. You know those were all things you don’t have to do. You would even do more than if you were at home” (5.008E–5.010E).

Sub-category 2.3.2 Making adjustments. Five of the residents talked about making adjustments or getting used to different things while living in the nursing home. It was an adjustment for one resident when staff had to care for other residents: “There’s no one here right now because they’re taking care of the other 14 or 15 people. You have to adjust to the fact that it’s not one-on-one, period” (10.021E). Adjusting to different activities that occur in the nursing home was considered “little tiny things” by one of the residents:

Well, uh...like I like to watch the news...you know...the world news...what goes on. Some would watch a game show...you know that’s what they want to watch. I like to listen to music...It’s too loud...you know...It’s just little tiny things, but I mean...but it’s something I’m adjusted to. (5.202AK)

The “biggest” adjustment for the resident was her loss of doing jigsaw puzzles which used to be an “outlet” to help her control her blood pressure:

No, I can't do it. I mean that upset me for a long time and I've decided there's nothing I can do about it, so I went into the word search. Well, I think that's the biggest one...and uh...I'd say my blood pressure...because it used to be a 150...could be a 160 if somebody bothered me...I mean it would show. And they...I think they took it yesterday and it was one 118 over 70. So you can see that I've made an adjustment. (5.203AK-5.05AK)

One of the residents got used to dressing in front of staff:

Well, I got use to that. Yea, you're not used to undressing in front of people, but it doesn't mean anything now. That's embarrassing. They have different ones here and it doesn't make any difference...not now. It did, but I've been here long enough now. You get use to them seeing you with no clothes on and...when you first do it, you're kind of embarrassed. (4.203AK-4.205AK)

Two of the residents found it challenging to learn the language used by staff in the nursing home: "They call dinner at noon...I call it lunch....They call that supper and I call that dinner" (3.023E). Another resident referred to different terms used for food served in the nursing home: "They give the doggone vegetables such names that you never heard in your life. You wonder what the hell it is. They said that's what they call it, so that's what we put on the menu" (8.006C).

Sub-category 2.3.3 Going to bed and getting up are different here. The bedtime rituals in the nursing homes were different from home for six of the residents. Going to bed earlier than the residents' normal bedtime surfaced in the six interviews. Getting up earlier in the nursing homes emerged in two additional interviews. Two of the residents enjoyed getting up early since they were accustomed to getting up early at home.

For one resident, the bedtime ritual in the nursing home was more like a hospital: "In my apartment, I didn't have to get up. If I wanted to lay [sic] in bed until 10:00 o'clock, I could lay in bed until 10:00 o'clock, but here it's more like a hospital" (4.237E). The resident further elaborated about being agreeable with the bedtime

practice: “Right after supper, why...I’m putting on my night clothes...Yea...that’s what I want to do” (4.130AD).

Another resident was not accustomed to going to bed so early: “Nobody would ever believe that I would go to bed at 7:00, 7:30 at night, but I do. They turn my television off...and here...I just go to bed. I wouldn’t do that at home...no way” (3.286AD–3.289AD). When asked how her bedtime schedule differed at home, she replied:

10:30 or 11:00...and here, just go to bed. They want to get my night clothes on me...so shoot...as soon as they get my night clothes on me...they get everybody around here...it’s quiet as can be by 9:00, 9:30. It’s quiet...you don’t hear nothing. I’m not missing anything...I’ve heard all of the news. I’ve heard the “Inside Edition.” I’ve heard the 6:00 o’clock news...and the “World News”...so there’s not much else to...except for some of that junk that’s on there (referring to television) and a lot of it is junk. But, uh... I would like to sit up and see some of...like “Dancing with the Stars”...I like that. I like “American Idol.” I like that, but I don’t see any of that anymore. (3.293AD–3.294AD)

She made the following comment when asked if staff were aware that she would like to watch the shows:

No, I don’t care. I can go to bed and some nights I fall right to sleep and other nights I don’t. I’m not going anywhere. I’m just going to bed. Here you go to bed when...the day is done, I guess. They get me ready to go to bed at 7:30. It’s fine and I’ll go to bed and lay there and I’ll fall asleep. (3.296AD–3.301AD)

Another resident made it clear that she disagreed with the bedtime practice at the nursing home and stated, “And I hate going to bed that early and then I wake up early in the morning. Yea...and it’s daylight when they get everybody ready and put them to bed. It’s horrible. I watch TV in bed” (2.140D–2.142D).

Implying that staff wanted the residents in bed early surfaced in another interview when the resident stated, “Go to bed 8:00 or 9:00 o’clock. And they want you to go to

bed so they can do their thing whatever that may be” (8.140AD). On the contrary, later during the interview, the resident seemed appreciative to learn that he could choose the time he desired to go to bed: “She said, ‘You don’t have to go to bed until you want to go to bed.’ I said, ‘Are you sure?’ She said, ‘Yes.’ So I can vary the time that I go (to bed)” (8.030K). He talked further about staff getting him up early in the morning though:

Now for some reason, something happens here that never happened over there where I was. They come in here at uh...25 after 4:00...maybe a quarter till 5:00, wash you up, shave you, dress you, and then put the covers back over you (chuckled), and then say they’ll be back in around 7:00 to take you to breakfast.

When asked how he felt about being awakened and returned to bed in the mornings, he stated,

I haven’t made up my mind (began laughing) about it yet to be honest with you. It don’t bother me (grinned). For some reason it doesn’t bother me. I lay here and turn my head and look at the clock, “Good God! They’re in here at 4:00...quarter after 4:00, 4:30, 5:00...somewhere in that neighborhood. What are they doing? (chuckled). But uh...so far it hasn’t bothered me, I’m usually awake for some reason when they walk in here. And then, you know...to make it where it should irritate me some, they come in, they throw the covers back and feel you to see if you’re dry or wet! Now that’s an experience that, uh...and I don’t think it’s ever happened to me! (chuckled). I don’t know what these are...to say...if they’re Depends or what they are, but yea, they’re supposed to take care of you if you have a mishap...let’s put it that way. They come in (grinning), “Are you dry or wet” and “I don’t know!” (chuckled). Not too dry! (laughing)...What the hell is going on? (continued laughing). No. And other things that they do that are pretty private does bother me, but they....okay, that’s their job.

One of the residents asked staff if she could remain in bed “a little longer” in the mornings:

I asked them if they...if I couldn’t stay in bed a little longer. I don’t think it’s necessary to get residents up so unusually early. I don’t like to get up so early. I never got up until about 7:00 o’clock, but, gee...sometimes they get you up at 5:00. I asked them if they...if I couldn’t stay in bed a little longer. (6.096AD–6.099AD)

In contrast to most of the residents' descriptions about getting up early, two residents enjoyed the nursing home practice of getting up early: "I always get up early in the morning, so if they come late, then I dislike it" (5.138AD). Another resident stated:

I try to stay in bed until at least 4:00 o'clock and then I get up and get dressed. Well, my day usually begins pretty early in the morning. I usually make it a practice to get up and dressed by 5:00 o'clock.
(7.085AD–7.086AD)

During the interview, he also stated "Well I've been getting up early...just about the major portion of my life" (7.120AD).

Sub-category 2.3.4 Comparing the nursing home to a hospital. One resident commented that the nursing home was "more like a hospital" when she described getting up early (4.237E), whereas another resident found the nursing home to be different from a hospital. She stated, "A hospital is not like home, and this is definitely not like a hospital although you can have the same care as a hospital if you need it" (10.154E).

Later in the interview, she stated,

I thought it would be more like the hospital. I've been at three different places in the hospital and they were...they're different than it is here....There's a different schedule than a hospital first of all and as nice as the people are at the hospital, this is more like the people who take care of you...as the neighbors who are coming in to help. They are people who are more interested in...not that they're not interested in the hospital, but they want to get you out of there as quick as they can. At the hospital, they want you to get well and go home. Now, I'm not saying they don't want you to get well here, but they accept the fact that you can't or won't be able to where at the hospital, it is get in and get out. (10.154E–10.159E)

Sub-category 2.3.5 Losing personal items. Losing important personal items was different when living in the nursing home for four of the residents. They seemed to accept the fact that the items would not be returned to them. One resident's wedding rings were stolen:

I had my rings stolen. Being stripped of my two rings...but actually there was [*sic*] four rings they took. I doubt that I will ever see them again. My son told me, "Mom, remember one thing: The rings meant a lot to you...Just remember, we three kids were a part of dad, too." It's something they can't control. I hold no judgment against the house. It wasn't their fault. I have nothing against the house. (1.104AF–1.109AF)

Another resident talked about losing clothing in the nursing home:

I know that I lost a shell like this (points to her blouse)...that isn't in the closet because they looked a couple of times and...it's lost. When I first came, I lost a pair of black pants. They never found those. Nobody ever found them. Nobody comes in weekly and so...I don't know if I lost anything or not. (3.312AF–3.315AF)

Losing various personal items was disturbing for one resident whose items were just "gone." She talked about losing a blouse and stated, "It was a nice blouse my sister had bought for me and, uh...I called it my Christmas blouse. But anyway, it's gone and when things like that happen, I think you just leave it go" (4.143AE). She repeatedly talked about losing things in the nursing home and stated:

It's not all good because you lose some things. I don't know if somebody likes them and...they...or...I never did get my blouse back...it's gone. (4.144–4.147AF)

Well, I'm not going to get it back. Somebody must have liked it. I'd love to have it back, but it's gone. (4.162AF–4.163AF)

Later in the interview, she continued to talk about additional things she lost in the nursing home:

I lost different things. That's terrible! You know you've got this and you know you've got that and...they're gone! (4.148AF–4.153AF)

My shoes disappeared...I didn't have any. Hey, it's awful to wake up at 2:00 o'clock in the morning, and you know your fan was sitting over there and it's gone! (4.159AF–4.160AF)

Collections that belonged to one resident were brought into the nursing home by his family and placed on display in the lobby. The resident seemed disheartened when he

talked about one of the items that had been stolen in the lobby: “Someone stole it...the flat iron...and I thought, why would anybody steal a dad-blamed flat iron, but they did” (8.143AF).

Category 2.4 Never-ending sorrow. The residents revealed never-ending sorrow when they discussed missing time with their families and missing home. In addition, living with other residents who required a higher level of care seemed difficult for some of the residents. Although all of the residents revealed empathy for residents who required higher levels of care, some of the residents assisted others by helping them in some way, yet other residents avoided them. The residents’ seemed to avoid residents who were “bad off” as a way to cope with fear of their own potential decline in health.

Sub-category 2.4.1 Longing to be with family and at home. One of the residents described a “good day” as a day when his wife visited him in the nursing home. He also repeatedly talked about being with his family and stated,

I enjoy my visits with the family. And that’s coming up. Easter and confirmations....Grandchildren being confirmed. I have so much fun with my grand- and great-grandkids...heading up to the lake...on the week-ends the kids are up there. It’s so much fun for me to watch them play (became tearful and holding head down; silence). (7.050S)

Another resident talked about missing adventures that included previous visits to his workshop at home. He described the meaning of adventure for him:

Oh...to go out to the garage and smoke a cigar. Oh my God, you can’t sit in the garage even though it has heat...and in the easy chair. That was our company. Oh no, they don’t offer that here. (8.193R)

One of the residents became tearful several times during the interview when she talked about her inability to attend visits outside of the nursing home because of her balance problem. Three residents expressed their family members’ concerns about safely

transferring them; therefore, they did not leave the nursing home. One resident stated she would not “push it” with her family even though she would love to return home for visits:

There’s a dining area here, but there it was Dennis and Doris and myself and the rest of the family sometimes, and I miss that and uh...I’ve asked a couple of times, “Well, couldn’t I get in the car and go out and spend an afternoon?” And Doris said she’s so afraid they won’t get me in and out of the car and I might fall. It worries her. They do have a wheelchair out there that I could use, but she’s afraid, and I won’t push it. (10.090S)

One of the residents stated, “I have very few company” (4.224AY). Later in the interview, she stated, “Anybody who comes in is my company” (4.225AY). She talked about family being unavailable to take her out of the nursing home: “There’s nobody to take you. My son moved to Illinois and he only comes to see me once a month” (4.226AY).

One resident perceived her family’s feeling of obligation to visit her:

I am bright enough to understand it’s an obligation and I hate to feel that. And I do not complain and I do not ask them to come any special time....I just tell them how much I appreciate that. They come to see me because they feel an obligation....They feel obligated...and I’m sorry it is an obligation to them. (9.111S–9.113S)

Another resident repeatedly talked about her family members; however, she refused their offer for her to join them for Easter dinner. She seemed to separate herself from her family when she stated: “She said to me the other day, ‘Are you going with your family for Easter?’ and I said, ‘No. I told my family I want them to spend Easter with their families’” (1.131S).

Sub-category 2.4.2 Having compassion for others. The residents spoke with compassion about other residents who required higher levels of care. They expressed gratitude about their own health comparative to most of the other residents. They seemed to segregate themselves from the other residents. Some of the residents stayed away from

other residents who had significant deficits. In contrast, two of the residents desired to help those residents who needed assistance.

Observing other residents who were “bad off” was so sad for one of resident who stated:

Thank God I’ve got my right mind. That is the saddest...seeing those people that just uh...are so bad off (whispers). There are people down at activities that are so bad off...oh, their minds. They don’t ...they just don’t know. It’s so sad. You can’t talk to people...I mean, they talk. Oh, they’re so bad off. (3.131U–3.136U)

She repeatedly talked about feeling sad for the residents who were “bad off”:

And watch some of those people....They require so much...and they can’t help it. It’s terrible....Their minds are so bad. They’re just so sad....It’s so sad to see those people who know nothing. It’s so hard to see those people down there...crying for somebody to take them to the bathroom. They cry that their feet hurt, their legs hurt...they hurt all over. Oh my...oh, it’s just so sad. It’s just so sad to see that. I can’t complain because I’m so much better off than some of them. (3.137U–3.145U)

Feeling “bad” for other residents surfaced in an interview when the resident stated, “I felt so bad for her because she had dementia. But without any children, I felt so sorry for her” (1.090U–1.091U).

The residents’ comparison of their own health to other residents surfaced again in two interviews. One resident stated, “I think that I’m healthy maybe more so than a lot of other people in this place. There are a lot of people that have a terminal illness... physically and mentally” (7.059U–7.060U). Another resident mentioned feeling sorry for others in the dining room:

We have people in the dining room that laugh loudly and talk loudly and uh...and then we have those who never say anything and they just sit there. That’s disturbing, too, because the only thing I can feel for people like that, or even the people that does the shrieking and the yelling...I feel sorry. You’ve just got to remember this may not be anything that person can help and aren’t you glad it isn’t you and aren’t you glad that what you

have wrong with you is not that...Well, it makes me feel very, very thankful and very grateful there are places like this. (10.091U–10.096U)

Later in the interview, she stated: “And there’s another lady in there, bless her heart, and she pushes everything she doesn’t want off the table onto the floor. I just think...well, it’s not me” (10.097U–10.098U).

Setting himself apart from other residents surfaced in another interview when the resident made the following comments:

Because I’m not like the other people in here! The way I look at it, uh...I’m a half-sane individual that’s been thrown into “One Flies over the Cuckoo’s Nest” comes to mind. That’s why I’m not like all of these people and you know, you put a high standard on yourself, you know. It was very difficult to be housed with a person who can’t talk. (8.118U–8.120U)

Sub-category 2.4.3 Keeping distance. Avoiding residents who were “really bad” surfaced in three interviews. The residents talked about staying in their rooms because they chose to be away from those residents who were confused. One resident stated, “Truthfully, I’m in here quite a bit...most of the time... (referring to her being in her room). You don’t want to go out there with people who have a screw loose” (4.082U–4.083U). She further stated:

Some of these people can’t be told or they don’t absorb it. I don’t even go out in the hallway at night after supper. They all sit out there until each one...they take to bed. Hey, I don’t want to see them. It would make me sick...that are really bad. I don’t want to be around them. I don’t want to be sick. (4.084U–4.085U)

She continued to talk about other residents throughout the interview:

It’s not that they’re nutty, but they’re....They don’t know what they are doing. They’re sick. Oh, I can’t stand them when they’re sick. I get sick, too. It makes me sick. Some of them don’t know....They don’t know which apartment that they live in. They don’t know how to get back to the kitchen. They just don’t know what they’re doing. That’s a sickness. (4.086U–4.089U)

Another resident stated that she preferred to stay in her room instead of joining the activities because some of the residents were so “bad off”: “That’s more enjoyment to me than seeing those people that just uh...are so bad off (whispers)” (3.133U).

In addition, another resident refrained from going to activities unless she could attend with someone who was not “completely out of it.” She stated:

I like my happy hour. I do not go unless I have somebody to go with. The host knows to seat you...and maybe with somebody who is completely out of it and I don’t want to do that. I am not Christian enough. I am probably not Christian enough to take them on and see if I can make them feel better. I don’t think I’m up to that...and I don’t know if it would make them feel better. If they want something, they go after it. (9.105U–9.107U)

She described a specific situation when another resident came into her room:

That man that wears the hat all of the time...came in here and, uh...I guess when I awoken from a nap, he propels himself with his feet and always wears a hat. There he sat...and I said, uh, “I think you must have the wrong apartment. Maybe you should go back to the hall,” and just...nothing, and uh...so I put on my button and they call...they came and they were chatting with me, and he said...he thought I was his wife. You can’t get involved in that. (9.108U)

She disclosed a sense of guilt for not helping residents who needed assistance when she repeatedly stated that was not “Christian enough.” She also stated, “Maybe part of that is my share that I should do, but anyway, I can’t do that” (9.109U).

Sub-category 2.4.4 Reaching out to help others. In contrast to avoiding residents who required higher levels of care, two residents desired to help them. One resident smiled as she talked about having dinner with another resident who had no one else to be with her. She stated:

[The other resident] said, “Well you’re going to be here with me then? Can we eat together? (smiles).” We eat together every day. I said, “Well, I will eat right beside you that day” and she was just so tickled. I made her happy. (1.094U)

Reaching out to assist others surfaced in one interview. The resident was “in charge” of other residents who needed assistance because she had special insight about what the residents needed during care. She felt rewarded when staff members asked her for advice about other residents and stated:

They become a little frightened and they don't know what's going on....They don't know what time it is to eat...just little tiny things that might not seem big to somebody else, but it is to them. The residents themselves think they can do certain things and you know they can't...A lot of these people...it really doesn't matter to them because they're not with it. (5.091U–5.094U)

She talked about ways that she assisted the residents who needed help and specified that staff members should “let them think”:

It's easier for them to work with me than with somebody else....You have to explain a little clearer to them than you would to somebody who's okay. Explaining more...don't tell them what to get, and try to get them to use their brain....You can suggest, but let them think...and that always bothers me...that somebody tells them. Tells them without letting them to think. (5.100U–5.105U)

Sub-category 2.4.5 Longing for things that are not here. Missing things from home that mattered to one resident surfaced in the interview when she talked about having no opportunity to choose things brought in from home. The resident referred to her family moving her into the nursing home in the following comments:

She put a lot of nice stuff in the Goodwill...which...I didn't like. There was more than one person that cleaned out my house. So hey, forget it. It's gone. They're gone, too (referring to her knitting needles that were in her previous room in the nursing home). (4.155F–4.157AF)

All of my stuff...at first they took stuff out, and told me they were putting it in a sale and they sold things for a nickel and a dime just to get rid of it. You couldn't get a bedspread that's gone...one that I made. You don't completely forget it. I can say that my stuff is gone, but it's still on my mind. (4.168F–4.171AF)

The residents expressed a desire for certain things that were not available to them in the nursing home. One resident would have liked a nice place to sit outside the building: “I think there’s some place that you should be outside on a bench, have a few trees, a park-like setting and a place to smoke a cigar” (8.077R). Another resident would appreciate a quiet area for dining and stated, “The other three ladies and I at the table in the dining room would like to be able to eat without having screaming sometimes from the people who are being hand-fed, and other disturbances in the dining room” (10.162U). She talked about a couple of other things that she would enjoy: “I’d like to have some cats around or brought in. They bring dogs, but they don’t bring cats...and I would maybe like to have a window somewhere I could put a birdfeeder out” (10.67U–10.168U).

For another resident, having pizza on Sundays like he used to have at home would have helped to make it a “good day.” He stated:

Well, they do have popcorn on Tuesdays...Now if they could arrange to have a pizza on Sunday, that would be good because my wife, we might sit in our Lazy Boy in our den, and I’d say, ‘Boy, I wouldn’t mind having a little Pepsi.’ She’d go get us each a little Pepsi and pop us some popcorn, so that’s a good day. (7.008E)

Having a private place to do jigsaw puzzles, which was a favorite hobby for one resident would provide the “outlet” that she missed. When asked if staff could assist in creating a way for her to do her jigsaw puzzles, she responded:

They tried, but there’s...You put up a table....These girls have to house-clean. There’s no way that they can...They had me going down in the great room...way down...but then that was down there. I mean they did try to make it...uh... You see where I sit...well, if I had to go down there, I’d want to go to the bathroom and have to come all the way back. And then...or if I’m down there and it’s time for lunch, I’d have to come all the way back. So I mean it was...it got to the point where I’d just do so much, but it wasn’t worth it anymore. (5.053M)

One of the residents seemed disappointed when staff members did not purchase word search books for her as they had intended when she stated, “[The staff] said, ‘We’re going to Dollar General today,’ but they never went. I asked her, ‘Well what did you find out?’ She said, ‘We never got there’” (4.108X). The resident also hoped to have a pair of shoes like the pair of shoes one of the staff members was wearing:

Because in there where you do the exercises, there was a girl in there and she had a cute pair of shoes on and I said, “Boy, I want a pair like that and I don’t care what color”...And she took my size and talked to the woman here, and this woman here takes care of your money and knows you get something that you want...from what...so anyway that amount of money goes into an account here and she can take that account and that will pay for my shoes...if she gets them...but my account will pay for them...and that’s important!...Well, that’s important...I’m not sure I’m going to get them...not yet anyway. (4.110X)

There were other things that some residents they could not get from staff members in the nursing homes. One of the residents informed staff members that she preferred the whirlpool where she could sit in; however, it was “real busy.” She stated, “So I don’t take it anymore. I wish that I could do it, but I can’t” (2.104V–2.105V).

Another resident referred to menu items when she stated, “They took it off so you can’t get that anymore. If you have only four or five that want grape juice, they’re not going to have grape juice” (4.102X–4.103X). She stated, “They’ll bring me a couple of cookies and uh, I’ll say, ‘Are they diet?’ If they say ‘No,’ then they’ll take them back out...so I don’t get nothing” (4.105X). She also described things she would like to have, but staff members could not buy them for her: “They don’t get nothing. The people who work here are not allowed to buy anything. I’ve even asked them to find me some socks” (4.009A).

One resident described her suggestion as “falling on deaf ears” of staff members:

If once in a while they would ask you, “Do you have any suggestions?” I know they said something one day about that and I said, “It would be nice if we had some hot rolls.” They said, “That’s a good idea.” Well, it fell on deaf ears....Nobody ever did that, so I’ll just have to mention it again.
(6.111AG)

Cluster 3: Relishing Good Care

Things that mattered to the residents during their care emerged in each of the interviews. Overall, the residents felt that all residents in the nursing homes were taken care of and their needs were met. The residents described feeling at ease to ask staff members for anything they needed. Good care occurred when staff members knew how to perform their care. The residents repeatedly talked about staff members’ training and expressed interest in staff members’ attaining further education. Feeling safe and secure also surfaced when residents talked about good care. The residents seemed to be intrinsically aware of staff members’ genuine compassion when caring for them. Newman (2008) described the development of presence that occurs when nurses are able to center directly on the patient and connect with the patient’s experiences. The residents described staff members’ presence when they went out of their way during care, took time to listen to them, acknowledged the residents’ concerns and desires, and were honest with the residents. Feeling a closeness and belongingness revealed a sense of presence as the residents talked about sharing stories about their families, education, pets, and friends with the staff members. The residents seemed to know work schedules of staff members with whom they grew close. They saved coupons for staff members and expressed concern when staff members who were close to them were not at work. It appeared that close relationships between the residents and staff members were more likely to occur when the residents’ care was rendered by consistent staff members. This finding is in

parallel with the first process goal of “Increasing Use of Consistent Assignment” identified by Advancing Excellence in America’s Nursing Homes Campaign (2013, para. 5). Eight categories were identified in the third cluster (See Table 8).

Table 8

Cluster 3: Relishing Good Care

Codes	Sub-categories	Categories
Everything is covered Majority are good They know what to do Counting on other people to help People work together	3.1.1 Being taken care of 3.1.2 Knowing that staff are trained 3.1.3 Appreciating staff who know how to provide care 3.1.4 Preferring routine of care 3.1.5 Having one staff member	3.1 Having good care
They are there when needed Help is there If I need anything, I can call them and get it		3.2 Having help when I need it
Somebody goes by and looks in They’re watching They keep a check on you	3.3.1 Feeling safe and secure 3.3.2 They are watching 3.3.3 They express concern	3.3 Checking in on you
Taking care of it They are caring	3.4.1 You can always go to them 3.4.2 Everyone is being taken care of here	3.4 Things are taken care of

Table continues

They're all nice people	3.5.1 Sensing	3.5 Feeling presence
Acknowledging concerns and desires	compassionate care	
Expressing interest	3.5.2 Cherishing warm relationships	
Feeling a belongingness	3.5.3 They ask me	
Feeling close	3.5.4 Going out of their way	
Sharing with staff	3.5.5 Taking time to listen	
Little things matter	3.5.6 Being honest	
Knowing staff like a family	3.5.7 Getting to know each other	
They ask me about my family	3.5.8 Having fun	
I ask them about their family		
Giving things to staff		
Being elevated		
They're understaffed	3.6.1 Doing as good as they can	3.6 Appreciating staff members
They work hard	3.6.2 Appreciating staff member's hard work	
Some of them have big workloads	3.6.3 Hesitating to call for assistance	
These people need a lot of work		
They try to please everyone		
Observing other residents who are not nice to staff		
I only call them when I have to		

Category 3.1 Having good care. The residents described various characteristics of what good care in the nursing homes meant to them. Being taken care of, training and education of staff, the routine of care, and having consistent staff members who knew how to render individual care emerged in the interviews when the residents talked about good care.

Sub-category 3.1.1 Being taken care of. Three residents talked about the importance of feeling “taken care of” as exemplified in the following comments: “Well, you’re taken care of. That’s what is important. I’m taken care of...I get my pills on time. I get my shots on time...they’re just here....Well, that’s very important...I can be

grateful...and they take care of me” (4.194AJ–4.196AJ). Another resident stated that the most important thing to her in the nursing home was that “everybody is being taken care of” (5.200AJ). For one resident, everything was covered: “Everything up here is pretty well covered. Everything that I like, that I appreciate is done” (6.085Z–6.086Z). She talked about a time when she needed assistance with soiled linens and stated, “They just picked it up and took care of it and I appreciated that” (6.087Z). Again, she stated, “I think things are covered um...pretty good here” (6.089Z).

Sub-category 3.1.2 Knowing that staff are trained. Three residents revealed a sense of comfort in knowing that staff members were trained. Training of the different interdisciplinary team members emerged in three of the interviews when the resident talked about therapists and nursing assistants. “Different people are trained....The ones in therapy are going to school...for a long time” (2.149AK–2.150AK). She talked about training of CNAs when she stated, “They have a class for the aides here....They are in some kind of class” (2.151AK–2.152AK). She also stated, “They get real good training here....They go to class. They get a lot of in-services that keeps them interested in going” (2.154AK–2.156AK). She also talked about “one girl” who was attending college and stated, “She’s going to college....She’s real good” (2.157AK). Because the resident repeatedly talked about staff members who were attending classes or going to college, she seemed to have a sense of pride for staff members seeking education.

Another resident described staff members’ training in how to handle residents: “They’re all trained and know what to do and how to do it and they walk him out. Oh, yea, ’cause they have to deal with them all of the time” (9.154AK). Another resident

stated, “Um, I think everyone who works here has been trained to their best ability and those who are at the top handle problems” (10.127AK).

Sub-category 3.1.3 Appreciating staff who know how to provide care. Staff members knowing how to provide individual care for the residents surfaced in seven of the interviews. According to one resident, most of the staff members know what they are doing: “They knew what to do” (2.026I). The resident talked about the importance of staff members knowing what to do during her catheter care:

They knew what to do. See, I have a catheter in and she knows what to do with it...knows the routine and emptying it. And I have support hose and they have to be washed out every night. Some do it, and some don't. That's the routine that some of them know and some don't. (2.027I)

She also stated, “That's the routine that some of them know and some don't...and wash your back. It feels good” (2.028I–2.029I). She proceeded to say, “So they know what they are doing. Most of them do” (2.032I).

Another resident described the meaning of staff members' knowing her food and drink preferences:

They know I drink cranberry juice. They always bring that to me...I don't have to ask for it. And they know that every Tuesday and Thursday, I order potato soup. They know that and they don't have to ask me....It's kind of nice they you that well. (3.032I—3.027I)

When asked why the staff members' knowing what foods she desired to have made a difference for her, she replied, “Knowing us [is] better than just...off the street” (3.045I).

She repeatedly mentioned how amazed she was that staff members' knew the residents names:

It's just amazing how they know your name and remember all of these...how they remember all of these people...I will never know. It's phenomenal! And that they remember everybody's name. How can you remember all of those people's names...I'll never know. (3.038I–3.040I)

In addition, staff member's predicting the resident's needs seemed important:

She knows exactly that I have to go to the bathroom. She comes in at 3:00 o'clock and by 4:00 o'clock, I'm ready to go down for supper and she comes at 4:00 o'clock....She'll even come back and say, "Joan, do you have to go to the bathroom." She comes and asks me....I don't even have to turn the light on. Because she knows me well enough that at 4:00 o'clock, Joan goes to the bathroom (referring to herself). I don't have to ring my bell nor nothing. (3.050I)

The importance of staff members taking care of one of the resident's colostomy surfaced in one of the interviews:

Um hum...about things that are not particularly nice to do. You know, that's no fun (pointing to the ostomy). Um hum...took care of it myself until I messed up my arm. They smile...of course they know what I want. Um hum...they come in all ready to take care of it. I don't have other things I ask for. (9.049I)

The manner in how staff members approached the resident during care seemed meaningful to her as she continued to talk about her colostomy: "This needs to be emptied (pointed to her ostomy bag). You can't miss it. They say, 'Okay, it's time to change it'" (9.053I).

She also found the staff members' knowing about her physical condition interesting: "When they know about you...physical conditions. It's interesting to uh...hear about any improvements and other people who had it and got along so well and that kind of stuff" (9.047I).

The meaning of staff members' knowing overall what a resident liked or did not like emerged in one of the interviews when the resident stated, "After so long, they get to know each patient and they know what they would like or wouldn't like. There's not too much that they don't know about me" (5.021I-5.022I). Staff members' knowing what the resident did not need mattered to one resident: "Well, they know I don't need

anything...don't need any help" (1.032I). The resident repeatedly talked about her appreciation of staff not bothering her.

Sub-category 3.1.4 Preferring routine of care. In addition to the residents who talked about staff members' knowing their routine of catheter and care needs, five residents talked about the importance of the routine in care. They seemed to appreciate having consistent staff members who knew their routine of care. When one of the residents talked about her catheter care, she stated, "That's the routine that some of them know and some don't" (2.027I). She described the reason it was important that staff members knew how to care for her catheter:

It has to be done a certain way. See, they took the catheter out and I couldn't go, so they put it back in. I have had it in and I have it changed once a month. I don't know if I will have it the rest of my life or not. I had a urinary infection last week. It's pretty well cleared up. (2.170I)

One resident stated that it means a lot when staff know her routine of care: "Those things mean a lot to a person. They know your schedule, and you know" (3.060I–3.061I). She continued to say:

But when you have somebody like that who knows your routine, then there's a...she's a going to...she has a cousin and she does the same thing, "Joan, do you have to go to the bathroom?" "Yes" (referring to her response to the aide who is a cousin to another aide)...She knows my routine, too, but I only have her a once ever... maybe a couple of times in a couple of weeks. But that means an awful lot...to me it does. (3.220I–3.223I)

Another resident talked about her care being automatic, on schedule, and organized: "It's kind of automatic you know...uh...I know when it's time to eat. I know when it's time for this or that or the doctor's coming" (5.025I). She proceeded to say:

I go to bed at a certain time. I get my medicine on time. In other words, uh...I don't miss...I go to exercise every day and I listen to trivia...and that's part of my routine. Whatever they've got, I know what's happening every day. (5.027I–5.030I)

When asked why the routine was important to her, she replied:

Because it's more organized. I get up to breakfast, lunch, and supper at a certain time. Some of these people don't get up until 11:00 o'clock to eat breakfast. I disagree with that. I think people should get up and get breakfast, lunch, and supper at a certain time so the body is adjusted to the...the day. (5.031I–5.032I)

The routine of care surfaced in another interview when the resident stated, “I think when they give showers and baths, it should be similar each time...close to the way it was the time before” (7.016I). Later in the interview, he also stated, “The fact that they don't know my procedures and my way of doing things...can be upsetting (7.083AB). He iterated that he would like an “everyday routine” (7.017I) and also stated:

Sometimes they don't know the proper routine that you're used to having. After the one time, and after that, they'll either ask you how or they'll just...I think they have a sheet of paper and they have it listed a lot of times...you know different things they should and should not do. (7.019I)

Another resident felt taken care of when her care was performed on time:

I come in here usually after my breakfast because you get up early...I get up at about quarter of 5:00 and by the time I'm dressed and uh then you have all of these nurses come in and draw your blood...well, you're taken care of. That's what's important. I am taken care of...I get my pills on time, I get my shots on time...they're just here. (4.232I)

Sub-category 3.1.5 Having one staff member. Having consistent staff members provide care seemed to promote a routine in care that mattered to the residents. One resident was discussing the importance of staff members knowing her routine and stated, “I heard another lady say, ‘Can we just have the same aide all the time?’ You can see that too...that they know your routine and they know what you require” (3.224I). Another resident relayed a message that she could rely on one of the nursing assistants when he was on shift:

He's just an aide, but he's the best one out of all. He beats all of them because he's there for everybody. He'll come....he'll come in and help you

and put you on the potty. Pull the string and I know he soon will be there. He will come. If he is here that day, he will take care of you. (3.183Z–3.188Z)

The nursing assistant predicting what care was needed without the resident informing the nursing assistant of her needs seemed important to another resident:

My aide that left, now she would always finish most of her people and would get...She'd come about 10 minutes of 11:00 and take me to the bathroom. I didn't have to tell her. She knew that I had to go to the bathroom 10 minutes of 11:00 because she went down to lunch at 11:30 and she knew that I had to go before I go down to eat. She would take her chance to take me to the bathroom and have me all done then she could go for lunch...at 11:30. Those things mean a lot to a person. They know your schedule and you know when you're going down to eat. (3.372Z)

She made the following statement about another nursing assistant who cared for her:

“You could depend on her coming in....I don't know her last name, but she was just a wonderful, wonderful lady” (3.194Z–195Z).

Staff members knew one resident's routine of care because they would “ask” the resident how to perform her care. She stated, “I like it when she's here” because of the “extra things” such as fixing the resident's hair (2.118Z–2.120Z).

The consistency of having one assistant seemed to promote building relationships in another interviews: “I've got the same girl most of the time. Yea, I like her...She's good to me. She's always happy....It just makes you feel good. Makes you feel good” (4.115Z). She referred to a therapist who assisted her with exercise when she stated, “When the girl's going to do it herself...well, I love that one” (4.114Z). The resident seemed confident when she described the driver of the facility bus who transported her to appointments. She relied on the driver to escort her to the areas she needed:

This is great. She does it all the time...take you to the doctor's office when I get my shots. It's really great...and then she brings me back. To me...that's great! When I go to the hospital...she's the driver. I go in the bus. She comes and gets me and takes me to the bus and when I get to the

hospital, she pushes me to wherever I go. That's important!
(4.117Z–4.119Z)

Category 3.2 Having help when I need it. Seven of the residents stated that staff were available to them when they needed assistance. The residents revealed a message of confidence that they would receive assistance or they could obtain items that they needed by asking the staff members.

Staff members' availability surfaced in one interview when the resident repeatedly stated, "If I need them all I have to do is say the word and they would be here" (1.045M).

Another resident repeatedly talked about staff being there for her: "But here they are around all the time and you call them...they come in right away" (2.056M). One of the residents described staff members' being there when she needed assistance: "Well, of course toilet-going makes it kind of frequent, so it isn't as though I didn't need them all of the time. I do, and they're there, and they're pleasant about it" (9.096M). She talked about nurses who attend that she felt would respond to her calls quickly if she would call them:

They'll come if I call...very quickly. I could call a nurse anytime I wanted to. I don't do that, so I would assume they would come. I feel sure they would come. I call them. If they don't stop by. (9.098M–9.099M)

Staff members may take a little longer, but one resident had confidence that staff would be there when she needed them: "So if you need help, there is always someone who can do that" (10.079M). She stated, "Anytime you need help, it's there and it's 24 hours a day. People care where they are always there and that's what you have here" (10.082M–10.083M). During the interview, she stated:

But I know when I ring, it may be, and I think that there are fewer on duty at night, so that maybe they're helping somebody else, so it may take a

little longer for them to get to me, but I know they will...And I have that confidence. (10.080M)

The residents' receiving things they asked for repeatedly emerged in the interviews. One resident stated, "If I want something, they would get it" (2.060M). According to two other residents, "If you ask for something, you'll get it" (3.085M), and "You can go over there and ask for anything and you know...they'll give it to you" (4.046M). During one interview, the resident recurrently talked about obtaining things that she asked for: "Anything that I ask for, they have it here...there's nothing that I can't ask for that I wouldn't get here" (1.050M–1.051M). Another resident talked about staff members getting things for her: "Do I want water...do I want this, you know...they're right there to get it for me" (5.054M). She provided the example of staff members' warming up a cup of tea that she was having during the interview and stated, "They'll come back and warm it up" (5.057M).

The manner of how staff members responded seemed important to another resident who stated:

If I was here, someone comes, and they don't just say, "Okay, what do you want?" They say, "Do you need some help?" That's the first thing that they say, "Do you need some help?" And if you say, "Yes, I need this or I need that," then they say, "Okay." If it is something they can do then and there, they do. (10.039K)

Category 3.3 Checking in on you. Nine of the residents talked about staff members checking in on them or watching them. The residents imparted a message of feeling safe and secure because staff members were checking or watching them. Three residents talked about staff members monitoring them because they were concerned about risk of increased weight loss, falls, and bowel assessments.

Sub-category 3.3.1 Feeling safe and secure. Being assured that the call light was within reach meant security for one of the residents who had a history of falling. She stated that she was “not alone” and “not ignored” in the nursing home (9.201J). She also made the following comments: “They do it...if I take it off, they pick it up and put it on me, or of course if it was bedtime, they put it on my pajamas. Security” (9.203J). Later in the interview, she stated, “Talk about security, it’s wonderful, if I fell again, I know it’s right here (pointed to her call light pinned on her sweater)” (9.204J).

Feeling safe and secure surfaced in another interview when the resident made the following comments: “It makes a person feel safe, secure, uh, if you can’t be, what you call at home, you can be safe at other places and this is it” (10.160J). She stated, “I feel very safe and very secure” (10.161J).

Sub-category 3.3.2 They are watching. One resident preferred that staff members not bother her by “asking questions unnecessarily” or being around “here all the time” (1.043K). However, she revealed comfort in knowing that staff members were checking on her at night when she stated:

They leave the door open ajar so the light comes in. I’m afraid of getting up and falling and so I keep the door open as much as possible so in case I need help. They have the light off or dimmed at night so it’s not real bright but they can see in. Usually in the morning...maybe 1:00 or 2:00 o’clock...the light goes on in the hallway and somebody goes by and looks into the room because anybody who has a wheelchair...I know over here, they go in there and change her because she’s wet, but uh....Other than that, they don’t bother me at all. That’s the way I like it. (1.033J–1.034J)

One resident talked about having a previous urinary tract infection and seemed to appreciate staff members checking the catheter: “They checked out my catheter last night and it was good” (2.033J). Another resident stated, “They’ve been checking me, maybe not every day. They’ve been checking me pretty often” (7.025J). He also made the

following comment, “Well, the nurses, they...they check the residents pretty regular” (7.026J).

It was important to another resident when the nurse assessed the resident’s experience of having chest pain. The resident stated:

They’ve got a nurse...when I said I had chest pain...she was right there. She checked me out. She took my blood pressure, she put that thing on my finger for my air...I think it’s to check my air. They checked me out and everything. (4.027J–4.029J)

The resident talked about another time when she became ill in the dining room and staff came “right away” (4.030J). She stated, “Yea. This place...they’re on the ball. Each girl has their [*sic*] job to do” (4.031J). She continued to talk about staff members watching her: “They come in here all during the night...bring their ice water and be sure you’re asleep...if you don’t feel good, you’ve got somebody that’s going to help you. They watch you really close” (4.034J–4.035J).

In addition, a resident talked about staff members watching her weight loss when she commented: “They’re concerned because I lost weight...they follow it up. They keep a check on you” (5.034J–5.035J). Knowing that staff members watch her vital signs was also important:

Um hum. And they say the temperature and I say, “That’s perfect!” They say “Yes and so and so.” And uh, blood pressure’s perfect. Of course it’s such a good feeling to know all of those things are alright and it’s a good feeling to know they’re watching. (9.058J)

The resident believed that others were not aware of how much staff members are watching them: “I think they stop and check you a lot oftener than we know” (9.060J). Staff members overall watch the residents according to another resident’s comment, “There are too many people. They can’t keep track of everybody, but they watch” (3.064J).

Sub-category 3.3.3 They express concern. Staff members' concern about the residents surfaced in three interviews. One of the residents revealed that staff members were "always concerned about you" (5.033J). She continued to talk about staff members monitoring her loss of weight. She provided another example of how staff members express concern:

Oh, if they saw a spot on you...like a sore...they follow it up. They keep a check on you...yes. To know they're concerned...um hum. That's where the family comes in. If you were at home with the kids, they would look out for you. Well, here, if they didn't, you'd be just another spot on the wall. (5.036J-5.038J)

Staff members were concerned about preventing overall resident falls according to one of the residents who stated, "And that's one of the things the nurses and nurse's aides hate to have on their record, that one of their people fell because of their negligence or because they weren't watching close enough" (7.078Z). Another resident stated, "They watch you really close. Your bowels...That must be real important because they keep that (silence). (4.035J-4.036J)

Category 3.4 Things are taken care of. Things were overall taken care of in the nursing homes. The residents described reporting concerns to nurses or administration that would take care of things that needed attention.

Sub-category 3.4.1 You can always go to them. One of the residents talked about a time that she was interviewed by the director of nursing when there was a problem with a staff member in the nursing home:

Yea, well they take of everyone. Now that one got fired. She was the one that was not real good. She was using her cell phone, you know, while she was supposed to be taking care of me and uh...I guess there were several complaints about her, but uh, they took care of that, and the director, Sharon Rockwell (fictitious name of director of nursing), she came up and talked to me. So it was the next day they got rid of that girl. I hated to say

anything about her because she did a good job, but she just wasn't appropriate for up here. (6.124AJ–6.125AJ)

Having someone to report problems to surfaced in another interview when the resident stated, “If anything happens to one of the nurse’s aides, they’re supposed to report it to Linda (the supervisor) or somebody who can take care of it” (7.110AJ). Yet another resident stated, “If anything that comes up among the helpers, aides, and so forth, those above seem to be able to talk to them and they work things out (10.033I). She also stated, “If a resident is not happy and there’s nothing that he or she can point to that’s bothering...to the people, first of all to your aide and then if they think it’s more important, uh...go higher still” (10.034I). For one of the residents, the administration provided consent for her family to take a bookshelf into her room: “When we said, ‘bookcase,’ well, she and the people higher up yet decided, yea there was room, so I had books (10.038K).

Sub-category 3.4.2 Everyone is being taken care of here. Two other residents reported to the nurses for support: “And the nurses are excellent. I mean you can always go to them for support if you need it. So I mean...it’s just like a family. You go to your mother or... to find out what’s going on” (5.004D). Another resident stated, “The nurse is a wonderful...If you have a complaint, you can go to them... Just told that. They receive that very kindly and pleasantly and uh operate on it...do something about it which is wonderful” (9.051I–9.052I).

Category 3.5 Feeling presence. Frequent descriptions of relationships that evolved between the residents and staff members emerged in the interviews. Sensing compassionate care, staff members’ going out of their way and taking time to listen to the residents, staff members asking residents about their likes and dislikes and being honest

with the residents led to warm relationships between the residents and staff members. The residents' descriptions were in juxtaposition with Newman's assertion that nurses being "fully present" is essential for establishing a connection with clients (Newman, 2008, p. 53).

Sub-category 3.5.1 Sensing compassionate care. In order for nurses to render compassionate care, unrestricted and meaningful participation must occur between the nurse and the client (Newman, 2008). The residents were able to sense staff members who were sincere about rendering care with compassion. Sensing compassionate care emerged in one interview when the resident made the following comments:

Yea...and they sort of try to tell you stuff that you should eat that would help. I mean there are...you have some dedicated nurses and you then you just have nurses...and there are two different ones. They're both nurses and they're both good, but one is better than the other. They have compassion. (5.122Z-5.123Z)

When the resident was asked, "How do you know if a nurse has compassion?" she replied,

Oh I know! (laughs). I can tell...you know uh...just like the one nurse...uh, my blood pressure...now I know that she's thinking of me. You know, she worries about me. I still have a nurse; she retired...she still calls me...Yea, and tells, you know... "How are you doing? Are you sure you're okay?" ...and does this often. (5.124Z-5.126Z)

One of the residents claimed that staff members knew what residents desired and needed: "I think they all know in their heart and in the back of their mind, they know...they know what people need and what they want" (10.105Z). She described the staff members' understanding of how she felt when she learned that she had a terminal illness:

I can't really say that they said or did...I can't think of anything they said, but they just seemed to understand. One of them said, "Well if that's what I heard, I'd feel a little bit upset maybe more than you do," and um, there

again, we talked and we decided, the two of us... and I began to feel better then. (10.049K)

Another resident talked about feeling uplifted when staff focused on her care:

There's one girl especially in the morning...a big tall, skinny Black girl...I don't know her name is, but she is very good about taking me and spending time with me, and I always say, "You've got other people to take care of," and she says, "But I'm taking care of you now" (emphasized "now"). Well that's just uplifting (smiled). (6.073Z)

Sub-category 3.5.2 Cherishing warm relationships. The residents' relationships with staff members seemed meaningful to them. Friendships that led to closeness between the residents and staff members surfaced in five of the interviews. One resident repeatedly described having a connection with staff members including the cleaning and maintenance staff: "I've been with her in some connection ever since I've been here. We're just good friends...hug... not mouth-to-mouth kissing, but face-to-face kissing" (9.029F–9.030F). She talked about relationships with staff again during the interview when she stated, "They like to come and kid everybody. It's just all a nice, warm relationship. The people that I know and love...it's just an ideal situation to sit and visit (9.190AI).

Descriptions of friendships with staff members also surfaced when the residents talked about having consistent staff members care for them. One of the residents made the following comment:

I have one girl especially...she's so nice...uh...she just tucks me in. She tells me about...uh...oh...what she likes you know, like the music that she likes and she told me yesterday that her sister was going to start working up here and she's been an aide for 15 or 16 years and she's going to be starting her or starts here yesterday and she was really enthusiastic about that. I thought that was nice of her to share that about her sister. Just generally nice and I think she likes me. I mean, I can feel it. (6.092Z–6.093Z)

When asked to elaborate on her statement about feeling when the staff are nice, she replied, “Well, they have a nice tone of voice. I don’t know...they give you little compliments. I don’t know...” (6.093Z).

One resident stated,

We can talk as friends. They tell me about um, their pets and uh their and one of them had a newborn baby niece and my goodness, she was so thrilled about that and so we talk about things that are happening and uh, I always ask them how they’re doing with their school work because the younger ones are all going to school. (10.111Z)

Two residents described having a sense of belonging or closeness as a result of staff members’ approach with their care. One of the residents stated that staff members’ knowing things about her, such as foods that she preferred, revealed “a closeness” with the staff members (3.345AI). She described closeness as “Like they are interested in you and know what you want” (3.346AI).

A sense of belongingness developed for one of the residents when staff members expressed interest in her family:

Well it feels like they think a little more about me than just being a resident up here. You know what I mean (smiles)...being a little bit belonging up here. Well they ask you about your family lots of times you know, and that’s a big thing to me. And uh, you know, they ask about my family and about the kids and what not and about my husband and all that and uh...they acted like they were generally interested in what I had to say. (6.121AI)

When asked how she knew they were generally interested, she replied “Well, it’s a feeling that you get when they’re talking to you.” She described other things staff members did to make her feel that she belonged in the nursing home:

Well, like when they help me in the bathroom and I have a lot of trouble...you know, hanging on, and my feet...they don’t work very well. They always will say, you know...nothing snotty about it or nothing. You know, they just...you know... “Just take your time...take your time.” Especially at night when you try to get up and move around and you’re

half asleep and they don't pressure you to hurry up. I always say uh, I just say, "Do as you can. I don't want to take you from other people," and they say, "Oh, no, that's okay. I'm with you now" (smiles). (6.072Z–6.073Z)

Another resident repeatedly talked about staff members' "including" her. For example, the staff members sometimes centered activities on her: "When they come up here to play music, they play something about New York. That includes me again" (5.018I–5.019I). The meaning of activities that focused on New York surfaced in additional comments: "They do it specifically for me" (5.023I), and "Mostly related to New York...because that's where I came from" (5.024I).

Staff members expressed interest in other ways such as inquiring about the residents' family members. One resident made the comment, "They like my family, my set-up, my...what makes my room home" (9.073K). She also stated, "They're interested in our families and they learn the names of them and where they live and what they do...which I think is pretty unusual because there are so many of us" (9.087K). The resident recurrently talked about staff members becoming friends with her sons:

He makes friends with all of them. They ask, "When's Robert coming back in?" I'm glad that he's that likable and that he's funny and they enjoy him. Well, they love to drop in when he's here and it's just all a good feeling. He makes good...The other one more even than Jeff (fictitious name of other son) make friends. They have more fun. Yea, they say, "When's Robert coming?" (chuckled). (9.088K–9.090K)

The resident seemed grateful that staff members provided a guest room for her son during visits: "And they let my son visit. I think he was lucky this time and got a room here. I'm sure he got a guest room this time" (9.085k).

A way that staff members expressed concern when they inquired about one of the residents who felt "down" about an ill family member was uncovered in one of the interviews:

He is blind in one eye and uh, when that happened, of course I was feeling down, and they said, “What’s going on?” and I said, “Well, you know...” and I told them and they said, (sigh) “What happened?” and “Oh, my goodness, is he still in the hospital?” “No, he’s still at home” and he’s recovering, but yea, we share....We share. (10.116Z)

Sub-category 3.5.3 They ask me. Staff members’ asking residents about their desires seemed to have enhanced presence in their relationships. One of the residents talked about the importance of staff knowing her routine because they would “ask” her about her about things such as what time she wanted to go to bed (2.118Z). Being asked to join activities was important to one resident who stated, “Well, when they ask me if I’d like to go down to mass, I like that. And sister comes up and gets us you know and takes us down there and uh I think that’s nice and caring” (6.087Z). She also stated, “Ask you what your likes are you know...you know, when I was younger what did I like...you know...did I like music or did I like sports and stuff” (6.079Z). It was also important that the staff asked her about her choosing her clothing: “They say, ‘Oh what would you like to wear today?’ instead of just picking something out” (6.082Z). In addition, the resident felt “elevated” when staff members called her “honey.” She stated, “Well it’s nice to be referred to as something...you know...a little elevated” (6.120AI).

Another resident described feeling important when staff members asked her for suggestions about what would be helpful during care of other residents. She stated, “Yea, in other words...what do you think they’d like to do? Yea, just all sorts of things...like activities...you know...just little things. They don’t mean great things. It makes me feel important” (5.181AI–5.183AI).

Using staff members’ names during communication promoted a “level plain-field” between one of the residents and staff:

After they serve you coffee, you thank them. You'd be surprised how they react when you call them by their names. Yes, then they come and ask you, "Vincent, do you need more coffee or..." and that works out pretty well. It is important to be on uh...uh...allows you to be on a level plain-field [*sic*] with staff. (7.029K–7.030K)

Sub-category 3.5.4 Going out of their way. Four residents talked about staff members going out of their way to visit them or assist them in some way. According to one resident, "They go by and say, 'Hi Vivian!!' That's lovely" (9.063K). She recurrently mentioned staff members stopping by her room throughout the interview: "They shout in the doorway all the time! And I wave with this hand! (held up her right hand). So it's all good!" (9.064K). "When they walk by and call in...that's pretty wonderful" (9.066K). "They're out here working, and they don't have me to do at that time. They'll circle in through the door and right back out....have a friendly word. Pretty wonderful (9.083K–9.084K).

Situations when staff members had gone out of their way emerged in another interview:

One of the girls who used to give me bed baths when I was at the other side of uh...the place, comes to see me. Now she doesn't need to do that, but she does. Not only she, but several of them do that. They come if they're working at the other end and take a minute to come over to say, "Hi" and if it's only a minute. (10.057K)

The resident described a social services staff member who "went out of her way" when she explained hospice care to the resident:

But I said, "I just don't understand all of it and I'm just not sure I want to be a part of it," and so then she told me what hospice does that helps them here and how they can help hospice in return and uh, by the time she got through, I had an entirely different feeling about the whole thing, and later on I was able to tell her, "Thank you," and she said, "Well I don't remember..." and I said, "Yes, you talked..." so, but she went out of her way that day when she found out how I was feeling. Now that, too, is caring....They do that all of the time. They do that all of the time. (10.058K–10.059K)

It was important to one resident that staff “recognized” her when she was in the halls of the nursing home: “They’re all great. They’re all nice people. It don’t matter how often you go down the hall, somebody that works here says, ‘Hi Jenna.’ and that makes me feel good...to have them recognize me” (4.041–4.042K).

Two residents talked about staff members from various disciplines assisting them:

And so many of the staff members do things you know outside of their realm. Like today, the priest brought me up from uh...oh...lunch...I was getting ready to go to lunch I guess and he brought me up here because I had to go to the bathroom before I went to lunch. So he came up and deposited me here which I think that’s pretty good! Sometimes the janitors help out. It’s all a part of [this] nursing home. (6.076Z–6.077Z)

Staff members seemed to go beyond their realm of duties in the nursing home for another resident who stated:

And it isn’t just those that come and do things like helping you get dressed and undressed and give a bath and so forth, it’s the people from the offices like the dietician and James (fictitious name of maintenance person)...I have no idea what that man does. He does everything I think. (10.117Z)

Another resident made the following comment about a nurse from a previous unit where he resided who frequently visited him:

In fact, one of the nurses from the old place where I was has been up here every night since I’ve been here... “How are you?” And she’s from Ethiopia, if you can imagine that. Who would have though you would have to come to this to meet somebody from Ethiopia, but a very, very, very nice person. (8.135Z)

Sub-category 3.5.5 Taking time to listen. Staff members’ taking time to listen to the residents surfaced in two interviews. According to one resident, nurses were supportive when “they’ll listen to you.” She stated, “Yea. If you have a question, you want to know the answer. And if they can’t find it, then they should find out....where I can get an answer” (5.109Z–5.111Z). Another resident shared the following comments about staff taking time to listen to her: “That’s friendship, um hum, and she does it

without my feeling...okay, I'm giving her a problem, um I'm taking up her time" (10.107Z). She also stated, "They'll always take a little time and listen" (10.110Z). She relayed a message of being welcomed to talk to staff when she stated, "She said you can talk to us, you can tell us what you need, and we'll do it if we can. If we can't, we'll just have to let you know it's impossible" (10.037K).

As one of the residents talked about a staff member who provided good care, she stated, "There's one girl...but she is very good about taking me and spending time with me" (6.091Z). One of the residents stated that she could go to the nurses for support. She conveyed a message that she could rely on the nurses to respond to her in a "motherly" way: "They're excellent....They're angels...like being very motherly....It's like when you were a child and you had a problem you went to your mother because she could give you the answer" (5.117Z–5.119Z).

Sub-category 3.5.6 Being honest. Staff members being honest with the residents came out in two interviews. The residents imparted a message of trust in the nursing home staff. One of the residents referred to the medical director who was on staff at the nursing home when she stated:

"We still do not know everything about the situation and what you have, what we have diagnosed, every...it seems to react differently with every person." So he said, "I cannot give you a direct answer for that." And I thought, well at least he's honest. He said, "We really do not know," and I...as far as that goes, I think that is caring, too, because if there was anyplace he could to find out, he would have. (10.055K–10.056K)

Another resident's wedding rings were stolen in the nursing home; however, she stated the nursing home was not at fault: "It's something they can't control. I hold no judgment against the house. It wasn't their fault. I have nothing against the house" (1.108AF–1.109AF).

Sub-category 3.5.7 Getting to know each other. The residents and staff getting to know each other seemed to enrich the resident–staff relationships. In addition to staff members getting to know residents by asking them about their likes or dislikes, taking time to listen to them, and going out of the way to make contact with them, the residents described conversations they had with staff members who consistently provided their care. They discussed the staff members’ schedules and talked about the staff members’ personal lives. At times, they expressed concern about certain staff members. Saving coupons for staff and sharing items with the staff members were ways the residents demonstrated thoughtfulness for the staff members.

The resident getting to know staff members also surfaced in the following comments:

She’s a young girl and goes to school and works part-time. She took Saturday off because she’s going out of town this weekend. She has a boyfriend. She’s at Shoreview College for her nursing. She’s going to go on and try to get a scholarship. (2.125Z–2.129Z)

Another resident stated, “I ask them about their family...she gets up at 4:00 o’clock every morning...she has two children and she said she gets their breakfast” (6.094Z). Getting to know all of the staff was important to one resident who stated, “I’ve gotten to know just about everybody up in...all the therapists...I go down the hall and wave. Everybody says, ‘Hi Vincent!’ (7.080Z).

Close relationships between the residents and staff members seemed to occur when the residents’ care was provided by consistent staff members. One of the residents shared the following: “My aide...she has two little boys...and she quit, retired...she’s just young. She’s going to quit for the summer to stay home and take care of her boys. She

waited on me every day” (3.189Z–3.191Z). The resident felt she could depend on this nursing assistant:

She’d be here every morning. You could depend on her coming in. I don’t know her last name, but she was just a wonderful, wonderful lady. She graduated...she was going to school. Mondays, Tuesdays, and Thursdays...she had off...and then every other weekend...and uh...I would always have the Sunday paper for her....I save all of the coupons for her because she gets diapers....Her baby is a year old. (3.192–3.197Z)

A connection with one of the caregivers surfaced in another interview: “She was the one that put her arm around me...That made her my friend” (4.121Z). “So every time I go by her, she’ll say something to me” (4.122Z). “I usually have the same person....She’s my same person” (4.123Z).

One of the residents talked about her conversations with some of the staff members and stated, “I have great-grandchildren about the same age as some of them” (10.113Z). “She knew their names, ages, and school activities” (10.1312AI–10.132AI). She expressed genuine interest in the staff members as exemplified in the following conversation:

The one who had the baby niece, my goodness, she went to her sister’s one day and was going to help her. She came in and I said, “Well how did it go?” and she said, “Oh I didn’t know that babies took that much care!” I said, “Yes, they take a lot of care,” but I said, “Do you mind?” and she said, “Oh no... I didn’t mind at all.” (10.114Z)

Sharing stories with staff members repeatedly came out in the interview:

One of them, bless her heart, she looks like she’s about 16 but I think she’s about 21 now, and she’s got a dog that’s almost as big as she is, so I’ve been told. I’ve seen pictures of it. It’s a great big lab. We talk about her taking this dog for a walk. (10.115Z)

In addition, the resident had given books to staff members whom she felt would use them: “They’re taking some books that I have to get rid of and I want to give them to people who will enjoy them” (10.143Z).

Another resident got to know one of the nurses who visited him:

I like her attitude. She told me, she said, “The husband is set wherever he’s going with his life. We’ve got the two kids through school,” and she said, “In about six months, it’s my turn.” I said, “That’s a good way to look at it, but just make sure that after that six months period of time, you’re doing what you wanted to do.” And I said, “I know it’s not leaving your husband or anything like that. I assume you want to become a registered nurse,” and she said, “No. I’m looking for something higher than that...Some kind of a doctor of some kind. (8.135Z)

Sub-category 3.5.8 Having fun. Five of the residents mentioned having fun with staff members. For one resident, receiving awards from staff members during activities was fun (4.188AH). Three residents talked about joking with staff members. One resident stated, “We can joke and they go past and wave...they always say I’m in trouble” (laughs) (5.046K–5.047K). Another resident talked about his frustration about not having enough information about the goals of a therapy session and stated, “They know how to bring you out of it...with a joke,” (8.184AE). He also seemed to enjoy challenging the staff members with his own jokes: “And I joke with them way too much, and I know that sometimes, they’re wondering, ‘Is he joking again?’ or ‘Is he doing this to irritate us?’ but, it’s fun...even though you really can’t say... ‘Ooo..that got to them!’” (8.189AE).

One of the residents stated, “I like my happy hour” and described it as a “fun thing” (9.104Q). She talked about different staff members having fun: “Even when they’re working with somebody else, they’ll call in....The exercise people, Evan and John, are real friendly and fun” (9.067K). She described staff members overall being “playful” (9.068K) and “fun.” Even when staff members remind her to use her walker appropriately, she stated that it is all in “fun” and stated, “We laugh” (9.069K). Staff members have fun during her care also: “I like the way they get me up, get me dressed, and have fun while they’re doing it and joke. Same way going to bed” (9.070K). Staff

had fun with the resident during other aspects of care: “And kind of fun and they’re fun doing it (taking vital signs)” (9.076K). “Some of them....see things that are funny and laugh with you...uh....It’s hard for me to put into words what you want to know. It’s lovely...fun things” (9.071K–9.072). Staff members having fun with her sons was especially meaningful to the resident. Perhaps her sons having fun with staff minimized her concern about their obligation to visit her. She stated, “He makes good...the other one more even than Jeff (fictitious name of son) make friends. They have more fun” (9.090K).

Another resident talked about having fun with staff members when she stated:

I kidded Landon (fictitious name of staff member) when, uh, somebody gave me this stuffed kitty cat over there (pointed to a black and white stuffed cat on the shelf near her television) and I asked him if I could keep a cat in here. He said, “No, no alive cats,” and I kidded him, I said, “When you go by my room, you stop and look at this one because it won’t give you any trouble. It’s quiet. It’s happy,” and so later on he stopped when I was in the dining room, he stopped and he looked at me and said, ‘I should have known!’ and he kept on going, but I mean, I don’t know...It’s nice. If I have to be somewhere, this is good. This is good. (8.053K)

Category 3.6 Appreciating staff members. Appreciating the care provided in addition to challenges that staff members endured came out in seven interviews. Overall, the residents felt that staff members performed care as good as they could considering their workloads. The staff members worked hard. The residents seemed distressed that staff members had encountered challenges of inappropriate behavior demonstrated by some residents. Descriptions of guilt were described by the residents who refrained from calling staff members for assistance because they felt staff members were too busy caring for other residents or they did not want to add more to the staff members’ workload.

Sub-category 3.6.1 Doing as good as they can. Two residents described insufficient staff to manage the workload in the nursing homes: “Some of them have big

workloads...not enough help. They do what they can do for me” (2.038L–2.039L). She repeatedly brought up the staffing shortage and stated, “They do as good as they can. They’ve got so many patients they can’t take too big of load at nights (2.043L). The resident suggested hiring more staff: “Get some more help. They could hire somebody who would be cheaper. They could get somebody who floats. They can get extra people (2.045L–2.046L).

Discussion about staff members doing the best they can emerged in another interview: “I think they do the very best they can, and I know too that sometimes they uh...the people who they’re helping become very disturbed, but they do what they can” (10.072L). She proceeded to say: “They do whatever they can to help” (10.073L) “and that’s what they do as near as they can...as near as they can. They can’t do everything” (10.075L).

A resident’s observation of the nursing home having insufficient numbers of staff surfaced in another interview:

They have a hell of a time getting people. The pay is not that great. Half the time, they’re understaffed. “Well I’m sorry, we’re going to get to you as soon as we can, but we’ve got three RNAs who are missing in action today.” I said, “Well, don’t that take you down pretty well?” “You’d better believe it”...so what could you ask for really. (8.040L–8.044L)

Sub-category 3.6.2 Appreciating staff members’ hard work. The residents stated that most staff members worked hard. One resident made the comment, “Lot of them work hard.” (3.066L) and then also stated, “Some of them work real hard. Others don’t” (3.067L). She recurrently mentioned care of the residents: “All of these people need a lot of work. The residents are different and require so much, too” (3.078L–3.079L). “And watch some of those people...they require so much...and they can’t help it” (3.080L).

The residents' seemed to be distressed about other residents' inappropriate behaviors with staff. One resident stated, "Sometimes people are not nice to some of the staff members" (6.043L). Another resident provided advice for residents who were inappropriate to staff: "He would get riled up. 'That don't work...you've got to learn those two words'...and then after you learn them two words, then learn their names" (7.033L). He was disturbed by some of the resident behaviors that he observed:

Some of the residents are guys are...one of the girls, he likes to touch her...I don't think that's right...but that's just the way he is...he's not been educated at all. The person that should be saying something is the person that he touches...And uh, if they don't say anything, then it's not...maybe harmful at all. (7.034L-7.036L)

Yet, he seemed shameful about the way he responded to another resident's inappropriate behavior:

And the nurse was in the room with me and she heard me say it. I said, "Bob is a dumb ass." I apologized to Bob. Well, it just happened and then you have to live with it...And hope it...hope it don't...the thing happen again. (7.040L-7.041L)

From another resident's perspective, staff members had a tough job:

They are very, very nice people that are here, and really, they've got a job to do that is to me, a very, very difficult job. Supreme Madonnas. I couldn't do the job for 15 minutes. Some of these people are terrible! Talk bad to the...I just couldn't put up with it. If it was me, I'd go in and slap her across the chops and render [*sic*] my resignation. I wouldn't last two minutes doing their job. I'd go stark-raving mad in two minutes, so...you know there are probably things I thought they could do and for some reason they chose not to...there again you know...you're just one person in here. (8.032K-8.036L)

The resident continued to talk about his observations of inappropriate situations: "Some of these people are terrible! Talk bad to the...I don't know what to call them...I call them CAN, I think" (8.037L). He mimicked other residents when he stated, "I want to be the first one up in the mornings. You get in here to take care of me...Well, you'd better hurry

because I'm sick and tired of it" (8.038L). He also stated, "There are some women in here, and men, who think the only people in here is them, and when they press that (looks at the call light pinned on his chair), it's about a minute, 'Where are they at? What are they doing?'" (8.039L). During the conversation, he seemed to also self-assess his behavior with staff:

I get to thinking that they're feeding maybe 300 or 400 people....How do you please everybody?...I've got to back off a bit of being so critical of their food and maybe most of the people here are so used to it. (8.044L)

Another resident recognized that staff members "have to deal with them all of the time" (9.093L). She seemed confident that staff "know how to handle them and what to say and how to do it and...it's a real satisfaction to see that taken care of that way" (9.094L).

Sub-category 3.6.3 Hesitating to call for assistance. Although the residents had previously identified a desire to perform their own care in order to maintain independence, their hesitancy to call staff for assistance because they were fearful of adding to the staff members' workload emerged in the interviews. One resident stated, "Well they're here to help...They are pretty good about answering the lights. Sometimes it takes them a little while. Sometimes they take the whole hall. I don't call them unless I need them" (2.053L).

Concern about bothering the staff members surfaced in another interview when the resident repeatedly commented about calling for assistance. She stated, "I don't put too much strain on these girls and the nurses because it's extra work" (3.065L). Later in the interview, she stated:

Then I've got to bother somebody...turn my light on...why bother them...they've got work to be done...If I was an aide, 'Oh what does she want now? That isn't necessary...She doesn't need a remote control....If

she goes to bed, she don't need to be watching that television,' (referring to what she perceives an aide would say if she called an aide in to take her remote control from her while in bed at night). (3.0831L–3.0834L)

Another resident iterated his desire to do things himself to prevent staff from taking their time to assist him in addition to remaining independent:

I don't want them messing with me and taking their time to do things that you can do yourself. You know, what's the point in that? That's stupid to me. And I don't want them doing things I can do myself. (8.035L)

Respecting the staff members' feelings surfaced in one of the interviews: "I try to be decent....They've got feelings too. So you try to be nice to them because they have feelings too" (6.037L–6.038L). Although the resident described a staff member who was inappropriate during care because of using her cell phone and communicating unprofessionally, the resident stated, "I hated to say anything about her" (6.040L). She also stated, "I just say, 'Do as you can. I don't want to take you from other people.'" (6.041L).

A feeling of guilt about calling staff for assistance was uncovered in another interview: "I felt guilty because she was very, very busy, but she kept asking questions and I gave her the best answers I could" (10.076L). She continued to talk about her hesitation to call staff members:

Uh, I just hesitate...I hate...I'll wait until I can't stand it anymore before I'll ring for anybody during the night because even though they're on duty at that time, maybe they're tired, too, so I don't want to them running unless I absolutely have to have it. (10.077L)

Her gratitude for the staff member's care frequently came up in the interview when she made comments such as "I appreciate everything that they're doing...yea" (10.078L).

Cluster 4 Getting By

In addition to the residents' descriptions of positive experiences while living in the nursing homes, opposing aspects of care that revealed challenges and frustrations emerged in the interviews. Some of the residents who made comments such as they "get by" or "let it go" seemed submissive about some of their challenges and frustrations. Getting by and letting go may be protective reactions in comparison to Newman's (1994) description of avoiding vulnerability. When persons are open with their thoughts and feelings, they become at risk for feeling vulnerable. Feeling vulnerable may cause suffering, which people often avoid (Newman, 1994). The residents imparted a message that it would be impossible for nursing home staff members to manage residents differently than what they observed in the nursing homes. Three categories emerged in the fourth cluster (See Table 9).

Table 9

Cluster 4: Getting By

Codes	Sub-categories	Categories
Different personalities	4.1.1 Getting along with other residents	4.1 Getting through difficult times
Letting it go	4.1.2 Getting along with staff members	
Getting past it	4.1.3 Some staff members lack education or training	
Forgetting it	4.1.4 Having different staff members	
Had to forget it	4.1.5 Waiting	
Good days/bad days	4.1.6 Getting upset at staff members	
Life goes on	4.1.7 Managing frustrations	
They're all the same		
Hanging in there		
Getting back		
Might offend them		
Making light of it		

Table continues

Being careful of what you say		
They think they know more than they really know		
They are kind of loud		
They don't care		
Inappropriate staff behavior		
Getting aggravated		
Getting annoyed		
They don't know my procedures		
You have to tell them		
Wondering when they will come back		
Feeling lost		
Being ignored		
They do not know what it is like		
Getting annoyed that they do not trust me		
Getting mad		
It's not my business		
Focusing on the positives (mindfulness)		
Finding spiritual strength		
Giving way to the rules		
Being on good terms		
They don't tell you	4.2.1 Wanting to know	4.2 Wanting more
Including more in activities	4.2.2 Desiring to learn more	information
Seeing no way things can be different		4.3 Wishing for things that are impossible

Category 4.1 Getting through difficult times. The residents made friends with other residents and staff members who were like a family to them in the nursing homes. On the contrary, residents' descriptions of getting through difficult situations involving other residents or staff members emerged in eight of the interviews. At times, the residents claimed to manage the difficult times by "getting by" or "letting it go."

Sub-category 4.1.1 Getting along with other residents. One of the residents

described his challenge of getting along with another resident:

This guy is hard to live with (points to his roommate)...the guy who stays in here. We had a little discussion...a heated discussion, but...nothing real serious. I tend to be able to get along with just about everybody (silence). I think that...I am hoping that I just move to that other room, or maybe Bob (fictitious name of his roommate) if he would go to another room or somebody else...I would rather be by myself or with a different person than sharing a room with him. I usually can get past those things. (7.087)

The challenges of one resident giving up her jigsaw puzzles when another resident repeatedly disturbed the puzzles repeatedly surfaced in an interview. Staff members attempted to find a solution by moving the puzzles to the opposite end of the nursing home; however, the resident found having the puzzles so far away from her room a burden and stated, “But it wasn’t worth it anymore...Yea, I did some pieces, but I didn’t enjoy it like I did when it was right there on my table” (5.140AE–5.141AE).

Another resident was frequently awakened at night by his roommate: “It was terrible you know...one guy that I had...he insisted that he could get on one of those trapeze-like things....and I heard the people arguing with him. Well, it woke me up about three times that night” (8.121U).

Observing other residents’ lack motivation in helping themselves seemed frustrating to two residents. One of the residents shared the following comment: “You can suggest and sometimes you could try until you’re blue in the face, and it just won’t go....It goes in one ear and out the other” (5.049I). Another resident talked about her frustration of hearing other residents complain: “People have their own minds. You can talk and talk and talk and some people...well, you and I both know, different personalities” (10.065L–10.066L). Further into the interview she stated, “I cannot

understand people who just...it seems as though they make everything unhappy around them and they...it's almost like they're working at it and I can't see that" (10.069L).

One resident was frustrated when other residents came to her about their problems in the nursing home. She wanted other residents to report their own problems to the staff members. She commented, "I speak up. That makes a difference" (5.128AB). She also stated, "See, if someone were like they were afraid they would say something, they might get in trouble. See where I say, 'Nothing's going to happen.' You need to put up you know, and say it. Don't tell me later" (5.129AB).

Lack of other residents speaking up surfaced in another interview when the resident made the comment, "But you're by yourself...Well as far as arguing...I don't hear any of the other people say...It feels like you have no back-up" (8.138AB–8.139AB).

Sub-category 4.1.2 Getting along with staff members. Although most of the residents developed warm relationships with staff members, challenges of getting along with staff members surfaced in the interviews: "And you do what you're told...if you want to get by" (8.164AV). This resident talked frequently about having no choice in situations because in general, things were done the way the staff members wanted them done. He stated, "Well, let's face it, you had no choice. But other than that, you or anybody else is used to....This is the way I do it...and this is the way I'm going to do it. No. This is the way you're going to do it. No. This is the way you're going to do it" (8.066P). In the following statement, he imparted a message of making himself get along with staff: "I knew that if it agitated them, there's no point...It makes me more amiable to uh...to say to hell with it. I'll get along...even if I don't like it" (8.012F). He further

stated, “I don’t feel that I have to get along with them anymore than they have to get along with me” (8.015F). The resident acknowledged challenges that staff members encountered as they provided care for other residents. Because of the staff members’ challenges of caring for all of the residents, he seemed to lack confidence that he would get to the dining room if he chose a time at his own convenience:

You think about how many people they have got to satisfy, or not satisfy, it don’t make any difference whether they have to satisfy you or not...you know, we’re still going to serve breakfast at 7:00 o’clock in the morning, we’re going to serve lunch at 11:00 o’clock in the morning, and we’re going to serve supper at uh...5:00 o’clock in the evening....Now you don’t have to go, but due to the fact that I have to have somebody walk me down...you’re thinking, okay, I don’t go this time...uh...when are they going to be able to take me? (8.077P).

The resident also talked about receiving his medications at times that were different than the schedule he expected and stated, “So I guess...I just...I just shut up. It’s either going to work or it ain’t [*sic*]” (8.141AE). “They give it to me...anymore...yea, and shut up...not argue about it” (8.142AE). He further elaborated on staff members’ making light of situations: “After a while, I just...don’t make me any difference...they could be on a nice silver face and make a joke out of it, laugh about it or something you know. In the main scheme of things, it’s really not important. Huh!” (8.186AE–8.187AE)

Another resident talked about “going along” with staff members:

I’m supposed to be walking as part of my therapy. I don’t take active therapy anymore and uh...uh, the therapists asked up here if they would find time to walk me and sometimes they say, “I’ve got too much to do. I don’t have time to do it with you.” And so some days I go by...days go by and I don’t do it all. I’m supposed to use my walker and then they drag along my wheelchair behind me. I walk down the hall and when I get tired then they let me sit down in the chair. And uh...it doesn’t take very long, but uh sometimes they can’t find the time to do that. (6.101AE)

When asked what it was like for staff to lack time to assist her to walk, she replied, “You just go along with it. Yea...I don’t raise any Cain about things” (6.102AE). When further

asked what it was like to go along with and not raise Cain, she replied, “It’s kind of intimidating for a while, but then I get over it. No, just to go along with it” (6.102AE).

Two residents relayed concern that staff members may retaliate if residents offended the staff members. One of the residents stated, “Well, you just don’t see eye to eye and uh...that happens once in a while with some of the nurse’s aides and uh...even have...with uh...nurse with me” He provided an example of not seeing eye to eye with staff members:

Well sometimes I might say something that I shouldn’t say and they might take offense to. Well this one time, this one head nurse was taking advantage of the nurses’ aides and the student nurses and bullied them a little bit even. I didn’t think that was right to do that. You have to be careful of what you say to somebody because it may backfire for you. (7.139AE)

In the following description, he revealed some humor although he seemed to internalize a staff member “getting him”:

I’ll tell you one of the things that happened I thought was kind of funny. Really it wasn’t uh...funny. During the early morning, I used the urinal and I rang the bell and I told them to empty and rinse out my urinal and bring it back. She brought it back and left about that much water in there (uses thumb and index finger to demonstrate approximately three inches). And then when I wanted to use it again and that just dumped right on me and uh...cold water at 4:00 o’clock in the morning did not feel very good, but I thought, you got me once...shame on me...get me twice...shame on you (chuckles). (7.092AG)

The resident provided advice for other residents so that they could get along better with staff: “I told several people that I...There’s two words you’ve got to learn: please and thank you. Everything else will get a little better” (7.028K).

Sub-category 4.1.3 Some of the staff members lack education or training.

Although the residents seemed to take pride in staff members who were in training or educational programs, a message that some staff members lacked training or education

emerged in three interviews. One resident lacked confidence in the training of some employees and stated, “Some of the employees I think are not really qualified to do the job” (7.090AG). He stated they were not qualified because “they don’t understand the procedures. I have a certain procedure that I want every day in the morning” (7.091AG).

Further into the interview, he stated:

Some of the nurses...you know, they have a certain responsibility. They’re not educated like they’re doctors, but they like to make people think they are. They wear that thing around their neck you know and they check your heart rate, but they really don’t know what they’re listening for. I mean some of them don’t impress me. (7.108AK)

When asked what nurses do that did not impress him, the resident stated,

Well, I think they should do check-ups once a week, my vital signs, blood pressure and heart rate, check my lungs, and breathing. A lot of times I don’t get that check-up like I think I should. So I am going to talk my doctor again and maybe he can put a bug in their ear. They...they pretty much listen to the doctor. (7.109AK)

He also stated, “I get a little bit disgusted with them...when they tell me certain things they’re not qualified to....You don’t have a degree in that...skin disease or anything like that” (7.095AG).

Disbelief of what a staff member reported to a resident surfaced in another interview:

She said, “Well, you just have to take it that I’m telling you and that’s it,” and I thought, hum....I thought...I thought, lady, you need some help because you’re not going to...I didn’t argue with her. I prayed because she’s going to come up head to head with somebody one of these days and they’re going to tell her, “You don’t know what you’re talking about and why are you out here? Why don’t you go somewhere else?” (10.124AE–10.125AE)

One resident was concerned about staff members’ lack of knowing how to appropriately care for her urinary catheter, so she showed them the correct process: “I’ll show them. It has to be done a certain way” (2.138AB–2.139AB).

Staff members' inappropriate communication was described by three residents.

According to one resident, staff members went "overboard" at times: "Sometimes I may go a little overboard with some things. 'Honey this,' and 'Honey that.' And I don't approve of that method" (7.100AG). Another resident stated:

I told them one time, I said, "This is a hell of a way to run a restaurant." They said, "You're not in a restaurant." I said, "What makes you think that? You order food, you eat, you're paying for it. You should render at least a bit of dignity to people who are eating here." But you don't...uh...sometimes it boils down to uh... "Are you done?" They don't give uh...to be patient...doesn't give a real concise answer, so...whew...the wheelchairs are away from the table and they're being escorted to their rooms. (8.145AG)

An additional situation when a staff member used inappropriate communication came out in another interview:

Yea, yea, and some of the things she talked about I didn't think she needed to be talking about like her boyfriend who would uh...she said uh...he couldn't wait for her to crawl in bed with him and be warm with him and all that kind of stuff. I said, "How long have you known him?" and she said, "Oh just a few days, but it seems like a year" and uh....This just wasn't the place for that. (6.137AG)

Inappropriate communication during care repeatedly occurred for the resident although she stated that she "left [sic] it go":

Well it was just last week...I had diarrhea (lowered her voice when stated she had diarrhea). And it came on in a hurry and I tried to get to the bathroom and I couldn't and I made a mess on the floor and the girl came in and uh...she wasn't my regular aide...I don't know who she was...and she looked at me and said...she said, "Oh sh--, oh sh--" (M. stated words emphatically). And I said, "I'm sorry, I couldn't help it. It just came on in a hurry. If I could have helped it, I would have." And uh...she went outside the door and she said, "She could have told me 25 minutes ago that that was coming on." And uh...so, I just left it go. (6.104AG)

The resident described another experience when she felt that she was putting the staff member out because of the inappropriate treatment and communication:

She rolled me over and she really pounced on my hip...I really yelled out and she said, "Oh shut up, you're waking up the whole floor." I just felt that I was putting them out. I mean, she was pretty gruff.
(6.105AG–6.107AG)

Although staff members working together to assist residents surfaced in the interviews, two residents shared their observations of lack of staff working together. One resident stated, "They don't help each other....well, some of them do. It's something about ambition...They don't care, but most of them care" (2.144AG–2.146AG). Another resident stated, "Lot of them work hard....Others don't amount to nothing and are just plain lazy. A lot of them are here just to...to have a job. But they should take care of that job" (3.316AG–3.316AG).

Sub-category 4.1.4 Having different staff members. The residents repeatedly mentioned their preference of having consistent staff members provide their care. They seemed to develop closer relationships with staff members whom they got to know. On the other hand, the residents revealed challenges when different staff members assisted them in care. The following comments surfaced in one of the interviews when the resident talked about having different nursing assistants provide her care: "Yea, they don't know what to do." When asked what it was like for her to have aides care for her who did not know what to do, she replied, "Like someone you can't tell anything to. Whatever they do, I just let it go" (2.143A). Having different "aides" surfaced in another interview when the resident stated, "Once in a while I get them myself and they don't take the best care of me...like some of them do" (3.318AG).

Different staff members providing care was uncovered in an interview again when another resident stated:

I had one special aide...every day I had...not every day you have a different aide...but usually you have a regular aide that comes here except

that she's off on the weekend. They're off one day and then the weekend. But when she's off, you get a different girl...different aide, but when that light is on, not just my girl should answer that light because maybe she's busy. The other girls out there...they should answer that light, but they don't do it (emphasized in louder tone). The light can be on....They walk right by. (3.179Z-3.181Z)

In the interview she repeatedly talked about the challenges of having different aides:

"I've had three different aides this week. So I've had three different aides this week...and all of them are different. They don't know what you want. You have to tell them the same thing every day" (3.270AB-3.272AB). Another resident commented about different staff members not knowing his "procedures," which was "upsetting" to him (7.083AB).

Two residents identified staff members' different personalities or attitudes. One resident stated, "A lot of them that take me on are real nice....They've got good personalities. Real friendly. They're easy to talk to and know what to do" (2.034K-2.036K). On the other hand, she talked about different staff members who "do not care" and stated they "ignored her" (2.143AG).

Staff members having different attitudes surfaced in one interview when the resident talked about a way that she cooperated with staff:

I think I cooperate pretty well. Attitude. Well, if I sass'd them back when they said, "Get both hands on there." You know I just have fun with it, and I'm not really annoyed so I appreciate...I appreciate the care. (9.035F-9.037F)

Yet another resident talked about staff members' lack of acknowledging her complaints about her charlie horses when she ambulated: "I have charlie horses...but it goes in one ear and out the other." When asked what staff did for her when she informed them about her charlie horses, she replied "Well they don't do nothing" (4.180AG-4.181AG). However, she continued to talk about ways that she rested as she

walked in the hallways and did not ask the staff members for assistance because of her desire to remain independent.

Sub-category 4.1.5 Waiting. Getting through the difficult times of waiting on staff members to assist residents came out in five interviews. One of the residents stated, “You always have to go to the toilet, and they don’t come sometimes as quick as you’d think they should. Sometimes it’s really hard. Sometimes you really have to go...but...I’ve always gotten through it” (4.124AA–4.125AA). She stated, “Hey, I just hollered, ‘I need help!’” (4.176AG). Another resident stated, “At night there’s only the one girl to help me. They’re all gone some place, and they don’t come back (2.134AA).

One of the residents stated that care was good although she frequently talked about the biggest problem for her was staff members’ lack of answering her call light: “You can sit here and hold it until finally...someone comes along...and feels sorry for you and takes you to the potty” (3.319AG). She repeatedly talked about “getting by” when she described waiting on assistance:

No...I just get by...and I am very thankful that I get by. It could be a lot worse. I don’t know if it could be any better...except I still say when you turn on that call light, somebody should take care of you. (3.013B)

Waiting on staff members to assist surfaced again when she stated, “You just wonder when they’re ever going to come back. You’re stuck in there....You sit there for 15, maybe 20 minutes, and you know they forgot you. I just want to get up and get out of there...been there long enough (3.249AG–3.251AG). She implied that staff did not know what it was like to wait on assistance to get to the bathroom when she stated, “People know that I take those water pills, but they’ve never taken water pills and don’t know what it’s all about. That’s right...and they’re not old like I am and their bladder’s weak...and the older you get, the weaker it gets. No. When you’re young, it’s altogether

different” (3.255AA). When asked what could be done to help staff members understand what it was like, she replied,

When you see a light on, make a stop...then see what the lady wants...because she probably just has to go to the bathroom. I heard one this morning...she said, “I’m all ready. I’ve got to have my pants changed.”...I heard one say that this morning (chuckles). (3.256AA)

She elaborated further about what it was like when she was forgotten and stated, “You’re lost. You’re just plain lost. It feels like they’re never coming back...and you can’t holler...hollered my guts out some times for somebody to help” (3.259AA–3.261AA).

When staff responded to her after hollering, she stated, “They say, ‘What do you want?’ (resident used a commanding voice). All they would have to do is look to see...and you...and they know what you want...to get up and get out of there.” When asked what it was like when they say, “What do you want?” she replied, “I understand how they feel, but they don’t know how I feel sitting there. And they bawl you out for hollering...I’ve gotten bawled out many times for hollering” (3.266AA–3.267AA).

Later during the interview, the resident mimicked staff members when she stated, “Oh, I’m sorry....Oh, I’m sorry. I’m so...I apologize from the bottom of my heart” (mimicking what she perceived a nursing assistant would say). “That’s what they would say. ‘I’m just so sorry’ doesn’t help me when I have to go potty.” When asked how she felt when staff did not return to assist her, she replied, “Just another one” (3.320AG–3.331AG).

The resident also talked about lying in bed for long periods of time: “They don’t get in here sometimes in the morning until 9:00 o’clock. By that time your back is about broke...you’ve laid so long.” When asked if staff members were aware that her back hurt, she replied, “Oh, why bother (states in low, whispering voice). It’s just tired from laying

is all. Doesn't make any difference...nothing they can do...just tired from laying"
(3.252AA).

Two other residents mentioned waiting on staff members. According to one resident, "You sit there and you eat, then you have to sit there and wait for one of these people...to finally dawn on them....'Oh, take Dale over to the dining room....I wonder where he's at now'" (8.137AA). Even though another resident described waiting on staff members, she commented that she did not care that she had to wait: "Another thing, too, is, you go down and you sit and you wait, now I don't care" (10.118AA).

Sub-category 4.1.6 Getting upset at staff members. Six of the residents described getting upset at staff members in the nursing home. According to one resident, "It's a good place...but I still got mad" (4.172AG). She frequently became upset when staff took items out of her room without informing her or asking for her permission:

When I get angry, I yell. I told them right out there, I said, "You don't hate me for yelling. This is a dump place....Get me out of here." I was that mad....I was ready to leave. She had no right to take them" (she referred to a staff member removing plastic bags from her wheelchair).
(4.173AG–4.174AG)

She talked about another time when staff members took her fan out of the room while she was sleeping and stated, "They just took them, you know,...but it wasn't okay with me" (referring to her fan). "They can't have it. I had to fight to keep it"
(4.178AG–4.179AG).

She became upset when staff members notified her son that she fell in the nursing home and stated, "What made me mad was they called my son. He lives in Illinois....I just did not want him to know....I didn't want him to know that I fell. It kind of hurts (describing what it was like when her son was called and she did not want him to be called)" (4.182AF–4.183AF). Yet another incident was upsetting to her when her shoes

and knitting items were lost during her move to a different room in the nursing home. She stated, "It made me angry" (4.182AF). She seemed remorseful about becoming upset and stated, "I don't want to be mad. I think it's important that everybody is happy...not worry about nothing. I like to love people....People will love me because I'm not a mad person" (4.185F-4.187F).

One resident stated that he was infuriated by his experience in the dining room:

They seem to want to move you out of the hall as quick as they possibly can...going even as far as cleaning your table while you're eating....Maybe it shouldn't, but that infuriates me. I don't know whether it bothered them or not, but it did me. My way of thinking is completely different from theirs. (8.150AG-8.152AG)

He also talked about his experience in the shower room:

They take you to take your shower, starts out nice and hot....This is going to be a good shower. About half-way through it, the cold water comes and you sit there like that while they're piling towels on you and uh....Why aren't they doing something about this?... You cannot make your body switch from hot to cold and do your body any good. In the first place, they've probably got their maintenance man working on it. I said, "You guys have been telling me that they've been working on it for a year!... They're trying to give us all pneumonia and kill us all off." (8.148AG-8.149AG)

Having a place for veterans to meet would have been meaningful to him: "It made me half-way mad to find out they had really no place for the veterans to gather among themselves" (8.153AG).

One resident found it annoying that staff members did not trust that she would dress herself when she could do so:

I got up and got dressed by myself and...I kind of hate to do it in a way cause then some of the smart ones...say, "You do it"...whether you feel like it or not or....They think, you know, that you won't if you don't have to. (9.173AG)

She also made the following statement:

Apparently, they think they're teaching me. Pretty annoying...because I don't think I'm...I think I'm doing what I can and I don't like to be treated as though I can't be trusted. I think some of them just feel their importance and are going to do it. (9.174AG-9.176AG)

Later during the interview, she brought up lack of trust again when she stated, "Well, it's a terrible feeling when somebody can't trust you...and I don't think I'm hiding anything" (9.177AG). She apparently did not trust the staff in working with her in some way to have an item in her room that she felt was not allowed in the nursing home:

I'm going to hide a couple of things, which we're not allowed here. That's what I miss from coming to this area because I understand it perfectly why these people can't have sharp utensils....It's very obvious, and uh...I did my fingernails with those little scissors that are about this long (indicates with finger approximately four inches)...Miserable. (9.178AG)

She also referred to staff members' lack of trusting her to take her medications without their observing her when she stated,

I would kind of like to have them completely trust me, but they don't know if I will quit being that reliable, so I understand. (9.179AG)

I would like to have them trust me that much, but I can see that they can't, so uh...They'll go and maybe be doing two of us at one time and uh...so they pretty much trust me. (9.180AG)

I say they can trust me, but it doesn't mean that they can. It's alright with me (9.181AG).

She proceeded to talk about laws in the nursing home.

I want them to trust me....I want it very badly, but there's laws. I think a lot of them don't trust you. It's their law and orders, and uh...furthermore, they don't know whether you're trying to achieve something by misleading or you really are losing it. (9.185AG-9.186AG)

Another resident became aggravated at first when she found challenge in resolving a problem with bringing in a bookshelf for her room. She stated, “You know kind of aggravated, I said, ‘Well what can I do...what can I do?’” (10.126AG).

Sub-category 4.1.7 Managing frustrations. The residents described managing frustrations in various ways. Focusing on positive aspects, finding hope in their religious beliefs, and finding humor were ways that residents seemed to manage frustrations. In contrast, some of the residents seemed to manage frustrations by letting go, getting by, or adhering to the rules so that they could get along in the nursing home. One resident seemed to find a positive outcome for any frustration she encountered:

Another thing, too, is, you go down and you sit and you wait, now I don’t care. I can sit and I can look out and I can....They planted flowers all around. I can look at those and the birds will come and I’m enjoying things. (10.121AE)

She further stated:

I know I can’t do anything to change what’s going on in the dining room. I just...if they’re a little bit late in the serving, I’m looking out, and uh huh, hydrangeas over in that corner are blooming, look at that! (chuckled). (10.122AE)

Focusing on positive things repeatedly came up in the interview:

It is pleasant if you make it so....Because everything is pleasant. You have to look for the good wherever you go. Just having the people around me who are pleasant, who help, and who are very willingly, gladly, with friendship and caring. (10.144AW–10.145AW)

I think that any place...I’m not familiar with any of the other places like this. I’m familiar with this and I love it. If I have to be somewhere, this is fine, but I think most any place, there are people who are loving, caring, and willing to help. (10.146AW)

You enjoy what you see. Next door there are two little boys. I’d say seven and 10...play ball over there, oh boy. Anything you can see that gives you something to look at and think about. That’s what you need to do. And you know, I mean that’s, if I can identify the flower, I even feel better. (10.147AW–10.148AW)

When asked what it was like knowing she would be in the nursing home forever, she replied, “You just take it day by day” (10.150AW).

Two residents frequently talked about their religious belief throughout the interviews. One of the residents became intermittently tearful when he talked about his religion:

The one thing I really believe is that statement up there on that...(looks up at a prayer posted on his bulletin board across from his wheelchair). ‘Do all things through Christ’ to give me strength. I have my beliefs and that helps me get through anything....I think my religion helps me.
(7.120AS–7.122AS)

Attending church service was repeatedly mentioned by another resident: “Well, the church is the most important thing” (2.160AS). She stated, “I was a member of St. Jude’s all of my life and went to these. They give a good sermon every day. It gives you something to think about all day” (2.161AS–2.163AS).

Two residents seemed to find humor in handling situations that were challenging or frustrating for them. One resident made the comments: “They’re just...one of the aides....They do different things to make my day not quite as good as what I’d like.” When asked to describe a time when his day was not good, he described the situation about the nursing assistant who left water in his urinal and stated, “but I thought you got me once...shame on me...get me twice...shame on you (chuckles)” (7.092AG). Another resident stated, “They know how to bring you out of it...with a joke. Well, then it became a battle of wits. After a while, I just...don’t make me any difference” (8.183AE–8.185AE).

Descriptions of frustrations were managed differently by other residents who seemed submissive at times. One resident stated,

I get by and that's the main thing...I just get by...and I am very thankful that I get by...that's okay...whatever they do...I don't care what they do. What have I done all day but sit here and eat? Sit here and eat! I'm not going anywhere. (3.352AV–3.357AV)

She repeatedly made the comments “I'm old, and it don't make any difference” (3.160AW–3.161AW), and “I'm hanging in there” (3.349AV–3.350AV). She frequently stated, “I get by...that's the main thing” (3.351AV; 3.353AV–3.354ASV).

Another resident repeatedly stated, “You've just got to along with it” when she talked about frustrations in the nursing home (6.101AE–6.102AE). “You go along with it” surfaced in another interview because there was no “better situation that would fit everybody” (8.169AW).

The resident who felt mistrusted repeatedly mentioned, “A law is a law” (9.189AG). Her plan to hide nail scissors may have been one way that she managed her frustration of feeling mistrusted. On the contrary, she stated that she understood the staff members' position about mistrusting residents.

Substituting activities that the residents could no longer do surfaced in three interviews. When it was frustrating for the resident who could no longer use her jigsaw puzzles as an “outlet,” she turned to “word search” (5.203AK). Two residents who recurrently talked about missing their gardens and being outdoors talked about watching the caretakers of the plants (1.095V) or viewing the plants in the nursing home (9.002B).

Category 4.2 Wanting more information. Six residents talked about their desire for more information. It was important for them to receive information about their care. The resident who was upset when staff members took the fan out of her room stated, “And most of the things here, they don't tell you. Why didn't they tell me? I wanted them to tell me. Now you can put on there (points to my paper and pencil that I was using to

record field notes), Tell people what's going on. I don't mean just about sickness and that goes too, but... (silence)" (4.234AX–4.236AX).

Sub-category 4.2.1 Wanting to know. Another resident expressed appreciation in knowing that she could have her nails groomed when she stated, "Somebody told me today that the nurse will do that, so uh...that's a good feeling to know that. I didn't know that" (9.200AX).

Questions may not be answered if staff members did not have the information according to one resident who stated, "If you have questions, they are answered to the best of their ability" (10.151AX). She also stated, "The answers are forthcoming if they have them" (10.152AX).

One resident described being noncompliant with occupational therapy because he did not receive an explanation for why he was asked to pick clothes up from the floor. He stated,

Later in the session, it must have been a week, they told me why they do that...Well, why didn't you tell me that to begin with?...You acted like it was a game, and it wasn't a game to me. I think had they told me at the very beginning...uh, is for the betterment of uh...your balance. But they didn't say that...just this is what we want you to do. (8.175AX–8.176AX)

Sub-category 4.2.2 Desiring to learn more. Two residents described their desire for continual learning. One of the residents felt unchallenged with the Bingo activity and stated, "You only have to know numbers up to 75 to play bingo (chuckled)" (7.132AX). He described spending much of his time viewing educational channels on his television and stated, "Well I am studying uh...German" (7.133AX). He also stated, "I think if I ever get pretty fluent in German, I might study Spanish. And if I was smart, I would start studying Chinese" (7.134AX–7.135AX).

Another resident talked about her desire to learn anything. “You know, to see the moon or something.” She’d do a “big thing about the moon...go into the Internet” (5.227AX–5.228AX). She desired more activities that engaged her in learning something new and made the following comment, “I’m not learning anything” (5.230AX). She stated that she desired “more activities where you could use your brain...doesn’t matter what it is, it could be about the ball game or uh...stuff to eat you know. It could be anything” (5. 234AX–5.235AX).

Category 4.3 Wishing for things that are impossible. Four residents implied that different ways of managing situations in the nursing home would be impossible to occur. Residents’ lack of independence, the requirement for different staff members to provide care for residents with various care needs, the ratio of staff members to residents, and residents’ becoming conditioned to living in the nursing home emerged as reasons changes would be impossible to occur.

After asking one of the residents what staff members could to make the nursing home more like home for her, she replied, “I don’t think they could. I don’t think they could...No, you couldn’t. It’s just different...that’s all....Independence” (3.024E). When asked what she could do to promote her independence in the nursing home, she replied, “Just accept it as it is. I couldn’t find a better place than this is. You won’t find a nicer, cleaner, place than this is....And you will find problems wherever you go, but I don’t have many complaints” (3.358AW). She felt that staff members were aware of the frustrations she described when she stated, “Yea, I think the majority of them do because there are all different kinds of people...some do...some don’t...but it’s staff and there’s just a difference.” She believed that staff could not make changes in the nursing home

when she stated, “I don’t know how they could. You’re dealing with all different kinds of people” (3.325AG–3.326AG).

Another resident described her dining room experiences, but implied that it would be impossible to be managed differently:

I don’t know if it’s possible, um...The other three ladies and I at the table in the dining room would like to be able to eat without having screaming sometimes from the people who are being hand-fed, and other disturbances in the dining room....That, I know, is an impossibility. I realize that. That’s one of the bad things. It’s something I don’t feel could be corrected. I don’t know what they would do. (10.162R–10.163R)

She continued to describe a specific situation that she would have preferred to be different in the dining room:

I don’t know if she has Tourette’s disease or not, but she’s constantly yelling at this one and that one, “Hey you!” or “Honey, Honey, Honey...” or “Hurry, hurry, hurry up”....It’s just a constant thing, and we’re sitting there trying to eat and have a little conversation now and then, and so we would both....All of us would enjoy something...but I know....I don’t think they can do a thing about it, and I wouldn’t even suggest it because it would be impossible. (10.164R–10.165R)

If you’ve got 90 people in there, you can’t serve them all at one time. There’s only three servers maybe, or four, and uh...yea something like that would fine if you could work it out, but I don’t think it could be. (10.166R)

Another resident inferred that submitting complaints would not make a difference when waiting on staff for assistance. She repeatedly stated that she “couldn’t complain.” When asked to talk more about her comment about not complaining, she stated, “Who are you going to complain to? You could complain, but...shoot...unless you go way up to the higher authorities and complain...” (3.285AC).

Residents become inured to living in the nursing home according to one of the residents. He stated, “I think there’s quite a few of them that don’t speak up. And it’s not because they’re afraid, what they proper usage, they’re brainwashed, and you get that

way” (8.183AW). His comment, “So you go along with it, because I am not sure I could sit down with a piece of paper and a pen and come up with a better situation that would fit everybody” (8.169AW). He inferred there could be no better situation in the nursing home. He acquiescently described his days in the nursing home:

Well, you get up to eat breakfast, you come back in here or go to physical therapy or whatever they have for you to do during that period of time and sometimes it’s nothing. Then eat uh...lunch. Same thing, then you eat supper...same thing. You’re in here then to watch TV. (8.174AW)

He acknowledged that he would not return home when he stated, “I’d go back there in a minute, but you’re not, and it’s hard to get that through your head....You’re not, you’re not going back there” (8.124V).

Summary of Results

Opposing aspects of things that mattered to residents while living in the nursing home emerged in the key findings. The findings revealed that the residents accepted living in the nursing homes because they felt they had no other option without burdening their family. On the contrary, they seemed dispirited due to having to live in the nursing homes. The nursing home became a “second home,” yet it was much different from living at home. The residents were grateful for their ability to perform self-care; however, they endured various losses including their inability to care for themselves without assistance. Receiving good care occurred for the residents, yet they endured frustrations and challenges sometimes during care. Some of the residents managed frustrations and challenges by focusing on positive aspects and others became upset or submissively “let it go” or “get by.”

The findings revealed the significance of person-centered care practices that include developing presence in relationships with residents. Residents shared stories with

consistent staff members whom they got to know. They enjoyed the integration of fun during care and sensed compassionate care. Appreciation for staff members who were trained and educated, and knew how to perform their routine of care was shared by the residents. The residents felt secure that they were watched over and their needs were taken care of.

Although it is not a part of the scope of this study, further understanding about why residents were compelled to respond submissively evidenced by their comments of “getting by” and “letting go” warrants further investigation. Finding ways to understand and assist residents to overcome submissive behaviors resonates with person-centered care practice. Understanding about the residents’ acknowledgment of a dire need for changes during their nursing home care, yet their considering it impossible for nursing homes to undergo such changes indicates a need for further education in nursing homes. Developing connectedness and understanding of what it may be like to be in the resident’s situations are essential for quality care in nursing homes. The opposing aspects of things that mattered to the residents in the key findings will be closely examined in Chapter Five.

CHAPTER FIVE. DISCUSSION

Residents' Descriptions of Things that Matter

Things that mattered to residents emerged in dichotomous descriptions of pleasure and contentment, and at other times of pensive sadness and regret. A brief summary of the key findings compared to Buhler's (1977) and to Carlsen's (1991) interpretations of things that matter are included in the discussion. Residents' descriptions viewed from a complementary perspective of positive and negative aspects derived from Kelso and Engstrom's description of "squiggle sense" also will be explored to illuminate how each aspect coexists in a dynamic way (2008, p. 186).

Findings from residents' descriptions of things that mattered to them while living in nursing homes contributed to ideas for operationalizing person-centered care. Suggestions for integrating elements of person-centered care in nursing education are included in the discussion. A discussion of all data that surfaced in the vast amount of findings is insurmountable; therefore, the discussion will center on key findings that emerged in each of the four clusters of data. Research, theoretical, and nursing implications are included in the discussions of key findings that emerged within the four clusters of data.

Comparison of the Findings with Conceptual Definitions of Things that Matter

Residents' descriptions of contentment and satisfaction were parallel with the "fulfillment pattern" described by Buhler (1964, p. 4). Residents described fulfillment when they reflected on the nursing home as home and other residents and staff members who became their family. Staff members' promoted residents' fulfillment in various ways that included encouraging the residents to perform as much of their own care as possible.

Residents' feeling safe and secure emerged in the findings when they described staff members checking on them and watching over them. Good care added to the residents' fulfillment when staff members took time to listen to the residents, acknowledged their concerns and desires, and expressed an interest in them. Staff members' acknowledging and welcoming family members into the nursing home seemed to add to residents' fulfillment. However, the residents yearned for additional fulfillment when they shared ways that staff members could have improved care. These findings revealed the importance for nurses to recognize residents' personal meaning derived from their values, purpose, and reality of the world as described by Carlsen (1988) and learn what the resident is about as described by Buhler (1977).

The Complementary Nature of Opposite Aspects Discovered in the Key Findings

Kelso and Engstrom (2008) claimed that opposite phenomena has a corresponding component that forms a "complementary pair" (p. 6). Viewing opposite aspects as complementary provides insight about each independent aspect coexisting in a dynamic way. Complementary pairs have been termed, "squiggles" symbolizing that opposites can exist with polarity and reconciliation (Kelso & Engstrom, 2008, p. 186). No opposite aspect is at a higher or lower level than the other opposite aspect. The tilde, or squiggle character (~), is used to represent the dynamic nature of opposites when revealing complementary pairs (Kelso & Engstrom, 2008, p. 40).

The following complementary pairs surfaced within and between the four clusters of data:

- Nursing homes became the residents' home, or second home, but they were different from home (nursing home as home~nursing home different from home).
- Residents felt that the nursing home was the right place for them to live, but they felt they had no other choice without burdening their families (right place to be~no other place to go).
- Residents described having independence because they had the freedom to go wherever they desired to go in the nursing home, yet they described loss of independence when moving into the nursing home and being unable to do the things they did at home (independence~dependence).
- Residents expressed gratitude for their abilities to care for themselves, yet they acknowledged relying on assistance for care (opportunities~limitations).
- Satisfaction and contentment surfaced in the findings when residents claimed to have few complaints, yet they described frustrations during care (satisfied with care~frustrated with care).
- Residents missed being with their families, but the staff and other residents became their "second family" (missed family~found a second family).
- Having sorrow for other residents repeatedly surfaced, yet most of the residents preferred to remain distant from others (feeling sorrow for others~keeping distant from others).

- Residents appreciated consistent staff members who knew how to provide care for them; however, some staff members did not know the residents' routine of care (staff knew their routine~staff did not know their routine).
- Help was available when the residents needed it, but at times no one was there to help them (help is available~no one was there to help).
- The residents sensed compassionate care although they described care that was not compassionate (care with compassion~care without compassion).
- Most staff members went out of their way to assist the residents, but some staff members ignored the residents (go out of their way to help~ignore residents when they needed help).
- Staff members' education in rendering care was important to the residents, but some staff members lacked education about care of residents (staff members were educated~staff members lacked education).
- Residents found ways to get along with staff members and other residents, although at times, they let go of various things in order to maintain peace with others (finding ways to get along~letting things go to maintain peace).
- Although residents became frustrated at times, they described ways that they managed their frustrations (feeling frustration~managing frustration).

Pesut (2010) suggested nurses use a complementary perspective to manage complex situations in nursing practice. A view of the key findings as complementary in nature is important for generating ideas about ways nurses may manage the positive and negative aspects of providing care for residents. Nurses may build on opportunities in the

nursing home environment to manage limitations during their care of residents. The dynamic interaction between residents' and nurses' perspectives of care could be a key element to successfully implementing care that is person-centered from residents' perspectives (staff members' perspectives~residents' perspectives).

Nursing Education across the Levels of Practice in Nursing Homes

The complementary nature of managing positive and negative aspects of care for residents is parallel with the need to integrate pedagogical strategies that prepare nurses for the complexity of care of residents. Nurses' ability to manage complex care needs of older persons rely on advanced nursing education that incorporates care of older persons in community settings such as long-term care (IOM, 2010). The findings of this study uphold the Baccalaureate Competencies and Curricular Guidelines for Care of Older Adults (AACN, 2010b) and Adult Gerontology Primary Care Nurse Practitioner Competencies (AACN, 2010a). These competencies and guidelines stipulate embracing patient-centered care and positive transitions and providing care with autonomy and non-coercive decision-making for older patients and their families. Initiatives in action for improving nursing education as a result of the IOM's reports, "Retooling for an Aging America" (2008) and "Future of Nursing Report" (2010), and the NLN report, "Recognizing the Vital Contributions of the Licenses Practical Nurse/Vocational Nurse" (2011) reveal an expectation that nursing programs integrate strategies for academic progression from beginner to advanced nursing. Learner-centered teaching methods that guide nursing students toward deeper thinking described by Sherwood and Horton-Deutsch (2012) may help students to invest in attitudes of embracing a person-centered care philosophy.

Improving nursing curricula rely on integrating teaching and learning principles that reflect a student-centered approach supported by evidence (Ironside & Hayden-Miles, 2012). Narrative and reflective pedagogies are examples of student-centered approaches that guide students to seek understanding and interpret meaning of situations that help them to begin “thinking like a nurse” (Tanner, 2006, p. 209). Students and teachers welcoming each other into a learning community encourage dialogue and reflection as they collectively explore and discern questions about situations (Ironside & Hayden-Miles, 2012). Students’ reflecting on clinical, simulation, and classroom experiences help to engage them in transformational learning where they can connect practical and theoretical knowledge. Reflection contributes to the students’ making sense of situations and pursuing ideal solutions that improve quality and safety during care (Sherwood & Horton-Deutsch, 2012). Reflection also facilitates the development of a deeper understanding of aging and professional and personal values about aging (Koh, 2011). Reflection can guide the students toward a deeper understanding of the complementary nature of positive and negative aspects of residents’ care. Students could gain insight from the positive and negative aspects of care revealed in this study. When staff members and residents developed close relationships, residents seemed more apt to find positive ways to manage their frustrations (opportunities~limitations).

Students’ reflecting on discussions with residents during learning circles provide them with insight about residents’ perceptions of what it is like living in nursing homes (Koh, 2011). Encounters with residents provide students with opportunities to learn residents’ unique cultural values, preferences, and life transition experiences (NLN,

2010). The findings of this study point out the importance of establishing close relationships with residents that lead to a deeper understanding of ways to help residents actualize self-determination. During this study, residents seemed enthusiastic to share their descriptions, and they expressed interest in learning about the study findings. Providing residents with an opportunity to share their experiences would help students to think about the importance of residents' knowing that their voice is heard.

In addition to direct communication with residents, technology such as virtual residents, computerized medical records, and hand-held devices are examples of innovative tools for students to use when they reflect on clinical, lab, and classroom experiences. Simulations that build on scenarios from students' experiences may provide an opportunity for students to think about steps they would take next during nursing care situations. Students' use of technology may provide them with additional time to analyze processes of care and make sense of situations as described by Tanner (2006). Using technology provides students with learning opportunities to think intuitively as they apply their own previous experiences of caring for older persons. In addition, technology would provide students with opportunities to keep updated about new methods and treatments available for improving care of older persons.

This study uncovered the importance of understanding residents' various losses when they transition into nursing homes. A focus on residents' losses in unfolding scenarios derived from the NLN's ACES framework (NLN, 2010) could guide students toward deeper understanding about residents' experiences of loss when transitioning into nursing homes. Likewise, embracing things that matter to residents in unfolding scenarios would lead students in identifying ways to perform care that is meaningful to residents.

Designing nursing curricula that includes students at different competency levels may enhance their knowledge, skills, and attitudes about the shared decision-making required in practice at nursing homes. In order to promote seamless academic progression for all levels of nursing competency, nursing programs are expected to include LPNs in curricular pathways for higher education (NLN, 2011). The continued rise of healthcare costs and complexity of chronic care needs will likely lead to increased use of assistive personnel and LPNs (Corazzini et al., 2013). However, it is important to include RNs and LPNs in curricular plans in order to promote education about collaborative, evidence-based practice nursing care decisions.

In nursing homes, most licensed nursing care is provided by LPNs (Corazzini et al., 2013; USDHHS CDC, National Center for Health Statistics, 2013). The IOM (2010) and NLN (2011) have emphasized the significance of LPNs' role in long-term care settings. In nursing homes, 22% of resident care is provided by LPNs, and 11% is provided by RNs (USDHHS CDC, National Center for Health Statistics, 2013) RNs attend two-year (associate degree) or four-year (bachelor of science degree) programs. LPNs are typically educated in technical or community colleges over a 12-month timeframe and learn to administer basic patient care and to report patient statuses to RNs and other healthcare providers (United States Department of Labor, 2014). However, LPNs working in nursing homes have administrative responsibilities six times more than LPNs working in hospitals (NLN, 2011). Nursing care decisions in nursing homes improved when LPNs and RNs practice within their scopes of education as designated by the state nurse practice acts (Corazzini et al., 2013).

Due to the growth of the elderly population with chronic healthcare needs, there will continue to be an increasing need to improve nursing home care. This study highlighted the importance of nurses' preparation to manage the positive and negative aspects of care for residents. Nurses can build on positive aspects of care by rendering care with authentic presence described by residents as staff sitting with them, taking time to listen, expressing concern, going out of their way to check in with them, and having an interest in them. Staff members' integrating fun during care assisted their building close relationships with residents. Nurses may be surprised to learn about residents' descriptions of intuitively knowing which staff members genuinely cared about them. Staff members who cared from their hearts seemed to have successfully invested in attitudes of person-centered where they got to know the residents. In concurrence, the residents seemed to know and care about these staff members. Residents openly communicated their losses with staff members who demonstrated genuine caring about them. This study revealed the degree of influence staff members have on residents' lives in nursing homes when residents felt they provided care from their hearts.

This study also pointed out ways that nurses can manage negative aspects of care by building on opportunities for dealing with care challenges. Including things that matter to residents during care can provide opportunities to help residents deal with frustrations. Providing residents with independence, self-performance of care, personal belongings from home, and integrating family in nursing home activities seemed to help residents deal with their losses and promoted their healthy transitions in the nursing homes. In order for residents to feel safe and secure, it is essential that care is provided by staff members who are trained and educated and who know how to provide residents' care.

Knowing that residents tended to react submissively when they experienced frustrations and let situations go in order to maintain peace and get along with staff provide nurses with a glimpse of residents' perspectives during care. The residents described a high respect for nurses providing care for them; thereby, nurses are in a prime position to assist residents to build on opportunities of establishing close relationships and promoting healthy transitions that may assist residents to manage their frustrations.

Key Findings

Cluster One: Accepting Life in the Nursing Home

Research implications. The key findings in cluster one highlighted the importance of nurses integrating things that matter from residents' perspectives during care to promote residents' healthy transitions in nursing homes. Lee, Simpson, and Froggatt (2013) discussed residents' anticipation about inevitably living in nursing homes, which led to their "resigned acceptance" (Lee et al., 2013, p. 54). However, residents moving into nursing homes who found ways to integrate past life experiences developed "healthy transitions" (Lee et al., 2013, p. 54). Conducting a study with deeper inference would be necessary to determine if the residents in this study experienced healthy transitions or resigned acceptance. In this study, residents seemed to develop healthy transitions when nurses provided them with individual preferences when making the nursing home like home, promoted their independence, and engaged them in close relationships. The residents were proud to share their personal items and pictures in their rooms. These things provided residents with connections to their past life that seemingly contributed to their accepting life in the nursing homes.

Theoretical implications. Newman described the importance of nurses and patients developing synchronous relationships when patients “lack connections” or “search for a place in world” (2008, p. 35). The nursing home referred to as home and staff members and other residents becoming family emerged in residents’ descriptions of accepting life in the nursing home. In concurrence with Newman (2008), and McCormack and McCrances’ (2010) descriptions of presence, the findings revealed nurse and patient connections with presence that contributed to “close” and “warm” relationships (resident interview references: 7.102AI–7.107AI; 9.190AI; 6.092Z–6.093Z; 3.345AI–3.346AI; 3.189Z–3.191Z; 3.192Z–3.197Z). Including things that matter in care provides nurses with an opportunity to learn more about residents and fosters close relationships between residents and nurses. Ideally, the constructs of person-centered care frameworks would include a therapeutic environment that integrates things that matter to residents in their care. The concept of healthy transition would expand current theoretical and conceptual frameworks of person-centeredness.

Nursing implications. It is essential that nurses practice care that is person-centered as opposed to performing behaviors that replicate person-centered care (Medvene & Lann-Wolcott, 2010). Nurses understanding that residents’ perceptions of care may be different from their own perceptions would likely occur during person-centered care practice. One resident cogently stated, “Of course, my way of thinking is completely different from theirs” when he talked about what it was like when staff members transferred him from the dining room prior to his finishing meals.

A squiggle sense of resident perception of care~staff perception of care brings forth the question: How can nurses gain insight about residents’ perspectives of care? In

this study, residents described sharing with staff members who took time to listen and engaged them in meaningful ways. Descriptions of nurses taking an interest in them repeatedly surfaced in the interviews. Nurses gaining insight about residents' perspectives of things that matter to them during care would most likely occur when staff members get to know residents. Residents talked about the meaning of staff members knowing about them and how to provide their care without asking the residents for guidance. These staff members seemed most dedicated to responding to call lights, knowing the residents' preferences, and developing close, warm relationships. Close, warm relationships between residents and staff members seemed to enhance the residents' transitions in the nursing homes.

Educating patients and families about planning nursing home care so residents make their own choices prior to nursing home admission may ease their transitioning into nursing homes. Inviting residents to suggest ways to make the nursing home more like their own home environment and including family members as part of the nursing home culture promoted residents' acceptance of living in nursing homes. Educating residents and families about available safe means for transporting residents may provide residents with opportunities to make visits outside of the nursing home, which would add to their healthy transitions and acceptance in nursing homes.

Cluster Two: Enduring Loss

Research implications. Necessary losses of physical abilities, death of loved ones, and independence as a result of adjusting to patterns of life that were different from home were similar to losses described as "sorrowful curtailments" by Pilkington (2005, p. 239). Pilkington's description of residents' attitude of serene acquiescence occurred

when residents found opportunities to gain power for moving on in their lives even though they experienced limitations in the nursing home. The concept of sorrowful curtailments and serene acquiescence were parallel with the key findings of loss and acceptance in this study.

Deeper insight into how nurses can help residents build on opportunities to manage limitations of living in nursing homes would add to current research. Residents' descriptions of loss and acceptance led to the question: What are ways nurses can help residents build on opportunities to manage limitations of living in nursing homes? (opportunities~limitations). Nurses taking a step back and reflecting on how they manage residents' care may help them to recognize ways for residents to build on their opportunities of independence that will help them to manage their limitations of living in nursing homes. Promoting residents' independence and self-care, and creating a culture of home and family, seemed to help residents attain healthy transitions. Residents talked about their personal belongings brought in to the nursing home, which seemed to help them make connections to their lives prior to coming into the nursing homes. Integrating family into the nursing home culture of getting to know one another was important to the residents. Scheduling consistent nursing staff to provide care enhanced close, warm relationships between the staff members and residents. Residents referred to close relationships when they talked about the nursing home and people there becoming home and family.

Theoretical implications. This study provided insight about the importance of understanding different types of loss that residents endure when coming into nursing homes. Finding deeper meaning about residents' various losses in nursing homes is more

likely to occur when residents share with nurses during synchronous relationships as described by Newman (2008). The findings add value for understanding authentic presence that is necessary to promote residents' openly talking about their losses. Necessary losses of inability to care for self, death of loved ones, and observations of other residents' regression seemed to underlie pensive sadness that surfaced in the interviews. Losses of personal items and an inability to obtain particular things desired in the nursing homes were described by the residents as feelings of frustration secondary to disappointment and anger. An intentional openness that should be the core of person-centered environments would support residents living in an environment where they feel welcome to open their hearts and share their losses with nurses.

Nursing implications. Residents openly described sharing their losses with staff members who demonstrated interest and took time to listen to them (presence~loss). Becoming aware of residents' various losses may provide direction for nurses to help residents manage their losses and enable healthy transitions. Although nurses are typically informed about residents' end-of-life wishes, this study revealed that nurses seldom discuss death with the residents. Loss of roommates and friends in the nursing homes repeatedly surfaced in the interviews, yet residents revealed lack of closure as they described not knowing what happened to those who were near death and transported to hospitals. Professional and ethical obligations that protect residents' confidentiality add to the complexity of care for nurses when sharing information that may assist residents to find closure after losing close friends in the nursing home. Engaging residents in rituals or memorial services for friends in the nursing home who have died may assist residents

in finding closure when losing friends. Residents and staff members sharing together during support groups may add to building close relationships.

Cluster Three: Relishing Good Care

Research implications. Warm, close relationships established among residents and staff members supported person-centered care elements described in the research. Providing residents with choices and using positive regard described by Grosch et al. (2008) emerged in the interviews. Residents described feeling empowered when staff members asked them about their desires during care. Residents appreciated staff members who expressed interest in them, asked about their families, and overall liked the residents as persons as described in positive regard by Medvene and Lann-Wolcott (2010).

Further research is warranted for addressing the question: How can nurses promote residents' asking for assistance in nursing homes? Perhaps successful operationalization of person-centered care that embraces environments where residents feel welcomed to ask for assistance would make a difference. On the other hand, residents established close relationships with many of the staff members, yet they often hesitated to ask for assistance. Residents talked about hesitating to ask for assistance because of bothering nursing staff who were busy. Some residents claimed to take care of themselves and called for assistance only when absolutely necessary. Because residents repeatedly talked about the importance of performing their own care, I wondered if asking for assistance posed self-doubt in their ability to maintain independence or to provide their own care. Finding ways to promote residents to ask for assistance may lead to fewer residents' injuries; thereby, improve quality of care in nursing homes.

Theoretical implications. The concepts of empathy, consistency, and reliability described by Winnicott (1970) and McGilton et al. (2005) repeatedly emerged in the findings. However, as a result of the qualitative method used in this study, rich descriptions of additional ways staff members provided good care emerged from the findings. Feeling presence, sensing compassion, cherishing warm relationships, observing staff members go out of their way, receiving honest information, sharing mutually with staff, appreciating staff, and having fun surfaced when the residents described relishing good care.

Guidance for establishing close relationships with residents during the interviews derived from Newman's (2008) theory of Health as Expanding Consciousness. Developing relationships with connection and presence enhanced interaction with the residents as they openly described their experiences during the interviews. Additional research is required for gaining insight about overall staff members' behaviors that lead to forming warm and close relationships with residents.

Nursing implications. Nurses are in an ideal position to role model person-centered care for other staff members (Medvene & Lann-Wolcott, 2010). This study highlighted the importance of the nurse attribute, authentic presence (Newman, 2008), that encouraged residents to openly share their feelings of loss with staff members (presence~loss). It was clear that the nursing staff members were performing various meaningful ways of rendering care for the residents. As I listened to the residents, I wondered if staff members were aware of the residents' feelings of closeness to them that grew from these warm relationships. Resonating with staff members during close

relationships seemed to promote residents' expanding consciousness wherein they viewed themselves as an important person within the nursing home family.

This study pointed out the need to investigate nurses' awareness of residents' perceptions of care. Nurses gaining insight into residents' perceptions of care may contribute to meaningful ways for nurses to individualize care, develop warm relationships, and reinforce their confidence about managing complex care for residents (resident perspective~nurse perspective). Nurses pausing and reflecting on the degree of consideration they have taken of residents' perspectives during care may prompt them to think deeper about rendering care that includes things that matter to residents.

Cluster Four: Getting By

Research implications. Residents' openly sharing with nurses surfaced as an opportunity for residents to manage frustrations. However, some residents managed frustrations during care by focusing on positive aspects in the nursing home such as finding hope in their religious beliefs or finding humor in situations. "Letting it go," "accepting it as it is," and adhering to the "rules" surfaced too frequently as ways residents submissively managed their frustrations. This study highlighted the need for investigating residents' submissive responses to frustrations during care.

Theoretical implications. Residents described openly sharing frustrations when staff members listened to them with presence. These staff members took an interest in residents and seemed to care about things that were valuable to them. The complementary perspective of resident values~nurse values that come together with neither one's values overpowering the other is integral to being "fully present" as described by Newman (2008, p. 54).

Nursing implications. The findings provided ideas for responding to an important question about care of residents: How can nurses manage residents' positive aspects~negative aspects of care? As mentioned previously in this study, there is an abundance of literature about the challenges of implementing person-centered care. In consideration of these challenges, Baker (2007) shared an important notion when she discussed the need for changing culture in nursing homes. She stated, "Fundamentally, the envisioned change is one of the heart, and the investment that is required is not so much financial as attitudinal" (Baker, 2007, p. 2). Residents intuitively knew when nursing staff provided care "from their heart." One resident eloquently stated, "You have some dedicated nurses, and you then you just have nurses...and there are two different ones. They're both nurses and they're both good, but one is better than the other. They have compassion."

The findings of this study provided ideas for educating nurses to invest in attitudes of person-centeredness. Integrating a complementary perspective of opportunities~limitations in care may provide new ideas for assisting residents' to manage their frustrations while living in nursing homes. Education that leads nurses to think deeper about how to provide an open environment where residents feel welcomed to share their frustrations supports a person-centered philosophy.

Limitations

Examining residents' interviews as accurately as possible for optimizing trustworthiness occurred throughout the circular process of collecting and analyzing the data. Limitations to the study included: (a) potential risk of reducing fittingness, (b) gaps in timeframes between first and second interviews, (c) interruptions that occurred during

the interviews, (d) potential undisclosed resident's fatigue during the interviews, (e) and potential nurse researcher influence on the behavior of the residents.

To assure fittingness during the sampling process, I disclosed the full scope of the study to administrators only during the nursing homes approval process. I informed nurses who provided names of residents that I was performing a research study requiring interviews with residents who had mild or no cognitive impairment. The nurses who provided the residents' names focused on selecting residents able to communicate their experiences. The richness and variety of resident's descriptions supported minimal risk of nurses' bias when they selected residents whom I invited to participate in the study.

Gaps of time occurred between the first and second visits for three of the interviews. My goal with each resident was to schedule the second visit within 7 to 14 days so the resident would be more likely to recall the discussion from the first visit. Prior to visiting the residents a second time, the interviews were typed, and the transcripts were sent to a second reviewer for additional feedback and suggestions. One resident was hospitalized during the time the second visit was scheduled. Two residents forgot the dates for the scheduled second interviews; therefore, they were not available for the second visit. Unexpected therapy and hair appointments, in addition to activities that the residents were attending, resulted in the need to reschedule.

Interruptions commonly occurred during the interviews. The residents chose to hold the interviews in their rooms. Interviewing residents in their rooms led to their sharing stories about family pictures and personal belongings that enriched the findings. Family members and friends who stopped in to visit occurred in two of the interviews. Two residents requested that the family members remain in the rooms during the second

interviews. Family members of another resident came in at the beginning of the second visit and declined the resident's invitation for them to remain during the interview. CNAs and nurses entered the rooms during several interviews to deliver ice water, snacks, or medications. When staff members entered the rooms, I paused speaking and let the resident determine whether the interview should continue. The residents directed the continuance of interviews by their responses when I asked if they would like to pause the interviews.

Fatigue may have occurred for one resident when she asked if she was done midway through the second interview. I did not correlate the resident's comment to her desire to end the interview at that time; thereby, I answered her question and continued the interview. The second reviewer pointed out the possibility that the resident may have desired to end the interview when she asked if we were done. I became more observant of residents' subtle comments and behaviors reflecting potential fatigue during subsequent interviews. During an interview, another resident commented about the approaching "lunch time." At that time, the resident agreed it was a good idea to continue the interview later in the afternoon.

Residents' knowing that I was a nurse researcher may have influenced residents' descriptions of things that matter. They may have altered their responses to accommodate what a nurse would expect rather than share their unique descriptions. Again, the richness and variety of resident's descriptions belies bias in the data. All but one of the residents seemed frank and genuine in their responses during the interviews. The first resident was hesitant to share negative aspects about anything in the nursing home. She made the comment, "I wouldn't make up something wonderful if it wasn't. In fact, I wouldn't live

here if it wasn't a nice place." The second visit with the resident revealed no difference in her responses about sharing negative aspects of living in the nursing home.

I remained careful about making comments that could lead the residents in their conversations. Assistance from the second and third reviewers provided guidance and additional suggestions for gaining clarity during second interviews with the residents.

The findings are transferable to residents above the age of 65 in the long-term care sections of nursing homes. Residents who had mild or no cognitive impairment were represented because they were able to describe their experiences. Each of the nursing homes incorporated a traditional model of care although one of the three nursing homes integrated an Eden Alternative model. However, this nursing home revealed a traditional model of physical structure with enclosed nursing stations at the end of each hall and used customary staff assignments.

Methodological Implications

Although concepts of empathy, consistency, and reliability surfaced in the interviews, rich descriptions of things that mattered to residents while they lived in nursing homes emerged as a result of the qualitative method used for the study. This study reflected on an abstract concept of things that matter defined by Buhler (1977) and Carlsen (1991). In contrast, McCormack and McCrance (2010) described "things" as a component of person-centeredness derived from Kant's objective definition that things are conditionally valuable and the value placed on things by a person relies on the person's circumstances (Paton, 1964). McCormack and McCrance's viewpoint of "things" based on Kant's definition reveals "extrinsic worth" (McCormack & McCrance, 2010, p. 39) that seems to lend toward an objective perspective of measures. However,

the description of things that matter derived from abstract constructs best supported the purpose of this study. Things that mattered to the residents revealed things that were most important to them and provided insight about what the residents were about as described by Buhler (1977) and Carlsen (1991).

Summary

The findings clearly support beneficence for residents when staff members rendered care with an investment in attitudes of person-centered care. Residents' emotions of pleasure and contentment, yet other times pensive sadness and regret, divulged a powerful message: Positive and negative things that mattered to residents influenced their well-being while living in the nursing homes.

Of major importance, this study provided direction for addressing the question: How can nurses manage residents' positive aspects~negative aspects of care? Assisting residents to build on opportunities that would help them manage limitations would lead to healthy transitions in nursing homes. The key findings revealed significance of humanistic caring when staff members formed close relationships with residents. The residents' intuitively knowing when nurses rendered care with authentic presence revealed the significance of nurses investing in attitudes of person-centeredness. Ideas for developing open environments where residents feel welcome to share their losses and ask for assistance when needed deserve further research focus.

APPENDIX A. PERMISSION TO USE PERSON-CENTRED NURSING FRAMEWORK

Re: Person-centered care model

<https://gwwa.ipfw.edu/gw/webacc?User.context=53d644d49be653ca6...>

Re: Person-centered care model

From: "McCormack, Brendan" <bg.mccormack@ulster.ac.uk>
To: reimern@ipfw.edu
Date: Tuesday - November 26, 2013 3:18 AM
Subject: Re: Person-centered care model
Attachments: TEXT.htm; Mime.822

Dear Nila

Thank you for getting in touch. I am very happy for you to use the model as long as it is fully referenced. Good luck with your research.

Best Regards

BRENDAN

**Professor Brendan McCormack,
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From: Nila Reimer <reimern@ipfw.edu>
Date: Tuesday, 26 November 2013 02:51
To: "McCormack, Brendan" <bg.mccormack@ulster.ac.uk>
Subject: Person-centered care model

Dear Dr. McCormack,

I am a student at Indiana University School of Nursing, Indianapolis, Indiana in the United States, and I performed a qualitative research study about things that residents state matter to them while living in nursing homes. I am integrating person-centered care concepts in my discussion. I found your Person-centered Nursing Framework (2010) in the literature and I find it supportive of my research findings. I would like to include a focus on your model in my doctoral dissertation in the discussion where I am comparing the components of person-centered care with things that residents identified were important to them in the nursing homes.

I am asking for your permission to use a copy of your model in my discussion findings. I would very much appreciate it.

Respectfully submitted,
Nila Reimer, PhD in Nursing Science Student

APPENDIX B. INSTITUTIONAL REVIEW BOARD APPROVAL



INDIANA UNIVERSITY

OFFICE OF RESEARCH ADMINISTRATION

To: SARA LYNNE HORTON-DEUTSCH
NURSING

From: IU Human Subjects Office
Office of Research Administration – Indiana University

Date: July 23, 2013

RE: NOTICE OF PROTOCOL RENEWAL APPROVAL

Protocol Title: Things That Matter to Residents in Nursing homes and the Nursing Care Implications
Protocol #: 1009001703 | 0811-01B
Funding Agency/Sponsor: None
IRB: IRB-01, IRB0000220

Expiration Date: July 11, 2014

The above-referenced protocol was reviewed by the Institutional Review Board (IRB-01). The protocol is approved as Active - Open to Enrollment for a period of July 12, 2013 through July 11, 2014. This approval does not replace any departmental or other approvals that may be required.

If you submitted and/or are required to provide participants with an informed consent document, study information sheet, or other documentation, a copy of the enclosed approved stamped document(s) is enclosed and must be used.

Please note that as the principal investigator (or faculty sponsor in the case of a student protocol) of this study, you assume the following responsibilities:

1. **CONTINUING REVIEW:** You must receive re-approval of ongoing research prior to the protocol's expiration date (noted above). You may receive a renewal reminder from our office approximately two months prior to the expiration date, however, it is your responsibility to submit the applicable protocol documentation to the IRB in a timely manner. If continued approval is not received by the expiration date, the study will automatically expire, requiring all research activities, including enrollment of new subjects, interaction and intervention with current participants, and analysis of identified data to cease.
2. **AMENDMENTS:** You must request approval from the IRB of any proposed changes to the research prior to implementation. An amendment form can be obtained at: http://researchadmin.iu.edu/HumanSubjects/hs_forms.html.
3. **UNANTICIPATED PROBLEMS AND NONCOMPLIANCE:** You must report unanticipated problems and noncompliance to the IRB according to the Unanticipated Problems and Noncompliance SOP, which can be found at: http://researchadmin.iu.edu/HumanSubjects/hs_policies.html.
4. **COMPLETION:** You must promptly notify the IRB when the research is complete. To notify the IRB of study closure, please obtain a close-out form at: http://researchadmin.iu.edu/HumanSubjects/hs_forms.html.
5. **LEAVING THE INSTITUTION:** You must notify the IRB of the disposition of the research when you leave the institution.

Note: SOPs exist covering a variety of topics that may be relevant to the conduct of your research. For more information on the relevant policies and procedures, go to http://researchadmin.iu.edu/HumanSubjects/hs_policies.html.

You should retain a copy of this letter and any associated approved study documents (e.g. informed consent or information sheet) for your records. Please refer to the project title and number in future correspondence with our office. Additional information is available on our website at <http://researchadmin.iu.edu/HumanSubjects/index.html>. Please contact our office if you have questions or need further assistance.

Thank you.

1 | c/o IU Human Subjects Office | (317) 278-7189 | irb@iu.edu

INDIANA UNIVERSITY INSTITUTIONAL REVIEW BOARD (IRB)

**CONTINUING REVIEW
OPEN TO ENROLLMENT**

Reviewing IRB (please choose one):

IRB STUDY NUMBER: 1009001703 (0811-01B)

Biomedical: IRB-02 IRB-03 IRB-04 IRB-05
Behavioral: IRB-01 IUB IRB

Please type only in the gray boxes. To mark a box as checked, double-click the box, select "checked", and click "OK". Please see the Continuing Review/Closeout Form Instructions for more information.

SECTION I: INVESTIGATOR INFORMATION

Principal Investigator:

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Project Title: Things That Matter to Residents in Nursing Homes and the Nursing Care Implications

Funding Source: _____ Sponsor Number: _____

Sponsor Type: Federal Federal Pass-Through State Industry Not-for-Profit Unfunded Internally Funded

Funding Status: Pending Funded N/A

SECTION II: CURRENT STUDY STATUS

ONGOING – OPEN TO ENROLLMENT

Date study was initiated: 2/18/2009

Projected date of completion: August 30, 2013

(Select one below)

Enrollment of new participants or review of records/specimens continues

No participants have been enrolled to date. Please explain, then skip to Section V: _____

Please check here if the study is currently suspended (temporarily) and indicate the reason(s) for the suspension:

SECTION III: SUBJECT SUMMARY

Check here if your study utilizes records or specimens versus human subjects. When the form asks for the number of subjects, document the number of records/specimens that have been reviewed or collected.

Check here if the IRB has approved a waiver of consent for your study. When the form asks for the number of subjects consented, document the number of records that have been reviewed or the number of individuals enrolled.

1. Subject Summary Table

		On-Site
Since last IRB review	Total number of subjects CONSENTED	7
	Total number of subjects who FAILED SCREENING (e.g. found ineligible to participate)	1
	Total number of subjects who have WITHDRAWN from the study	0
Since beginning of study	Total number of subjects CONSENTED	11
	Total number of subjects who FAILED SCREENING (e.g. found ineligible to participate)	1
	Total number of subjects who have WITHDRAWN from the study	0
Number of ACTIVE subjects		1
Number of subjects who have COMPLETED the study		9

If necessary, please provide further explanation regarding the subject summary: **One participant agreed to participate in the study and signed the consent forms; however, the participant did not meet the required score on the Montreal Cognitive Assessment (MoCA). The required score for determining mild or no-cognitive impairment on the MoCA is 18 or higher out of a possible score of 30. The participant's score was 13.**

2. **Withdrawal.** Have any subjects withdrawn from the study since the last IRB review?
 No
 Yes, state the reasons for withdrawal: _____
3. **Justification for Study Continuation.** Have subjects accrued in the study since the last IRB review?
 Yes
 No. Justify study continuation: _____
4. **Vulnerable Populations.** Are any of the subjects who have consented or enrolled in the study members of a vulnerable population?
 No.
 Yes. Has the IRB previously approved enrollment of these subjects?
 Yes. Continue to Question 5.
 No. **You must submit an amendment to the IRB to request the inclusion of these subjects.** Subjects in the the following vulnerable populations were enrolled without IRB approval.
 Children Pregnant Women and Human Fetuses
 Prisoners Economically/Educationally Disadvantaged
 Cognitively Impaired Students
5. **Short Form Consent.** Were any subjects consented using the short form written consent document?
 No.
 Yes. Please describe the circumstances of each subject enrolled, including language in which the consent process was conducted: _____
 Is there a reasonable possibility that additional subjects who speak this language could be enrolled?
 No.
 Yes. Please submit a translated version of the IRB-approved consent document for review and approval by the IRB.
6. **For studies employing waivers of assent:**
 a. State the number of assent waivers that were employed since the last IRB review: _____
 b. Explain the circumstances surrounding each assent waiver employed: _____

SECTION IV: ETHNIC/RACIAL REPORTING REQUIRED FOR FEDERALLY-SPONSORED AND VA STUDIES

This study is not federally sponsored nor a VA study.

SUBJECT ACCRUAL		
Ethnic Category	Sex/Gender	Total

	Females	Males	Unknown or Not Reported	
Hispanic or Latino				
Not Hispanic or Latino				
Unknown (Individuals Not Reporting Ethnicity)				
Ethnic Category Total of All Subjects*				
Racial Categories				
American Indian/Alaska Native				
Asian				
Native Hawaiian or Other Pacific Islander				
Black or African American				
White				
More Than One Race				
Unknown or Not Reported				
Racial Categories Total of All Subjects*				

If ETHNIC and RACIAL category totals are not equal, please explain: _____

- Have there been any unexpected problems recruiting participants, especially subjects in a particular category (including children and women)?
 - No.
 - Yes. Please explain: _____
- Is this study conducted at, funded by, or recruiting from the VA?**
 - No.
 - Yes. In the table below, please indicate the total number of VA subjects enrolled in the study and indicate in which categories those subjects fall and how many represent each category indicated.

Total number of VA subjects: _____

<input type="checkbox"/>	Children:	_____
<input type="checkbox"/>	Cognitively Impaired:	_____
<input type="checkbox"/>	Economically/Educationally Disadvantaged:	_____
<input type="checkbox"/>	Pregnant Women and Fetuses:	_____
<input type="checkbox"/>	Prisoners:	_____
<input type="checkbox"/>	Students:	_____

SECTION V: STUDY SUMMARY OF EVENTS

- Since the last IRB review**, did any unanticipated problems, including adverse events, protocol deviations, or subject complaints, or noncompliance occur that required prompt reporting to the IRB?
 - No.
 - Yes. Were these events reported previously to the IRB and VA, if applicable?
 - No. Please explain why these events were not previously reported: _____
 - Yes. Provide a **summary** of these events: _____
 - Check here if the **summary** is attached.
- Since the last IRB review**, did any protocol-related adverse events, subject complaints, or protocol deviations occur on-site that did **not** require prompt reporting to the IRB?
 - No.
 - Yes. Provide a **summary** of these events: _____
 - Check here if the **summary** is attached.

3. Is there a data safety monitoring plan for this study?
 No. This study is minimal risk (exempt or expedited).
 Yes.
 Does the plan include a data safety monitoring board?
 No. The principal investigator and co-investigator will be responsible for the data and safety monitoring. There will be no additional committee or individual that will be responsible for monitoring the data. A research assistant may be hired to assist with typing transcripts. The principal investigator and co-investigator will be responsible to monitor the data transcription. The principal investigator and co-investigator will assure that the data accessed will be de-identified prior to sharing the transcripts with the research assistant or research team members.
 Yes. Please provide the most recent monitoring report if it has not already been provided to the IRB or explain why one cannot be provided: _____
4. Based on the above information, do you feel the validity of the data is affected?
 No.
 Yes. Explain: _____
5. Based on the above information, do you feel there is an increase in risk to subjects or others or in the frequency or severity of adverse events, protocol deviations, problems, complaints, etc. since the last IRB review?
 No.
 Yes. Explain: _____

SECTION VI: SUMMARY

1. Describe the progress of the research, including any preliminary observations and information about study results or trends: Repeated data findings reveal positive and negative things that the participants described while living in the nursing homes. Redundancy of codes have emerged from the data findings throughout the interviews.
 If no progress description is provided, please explain why: _____
2. Have subjects experienced any **direct** benefit(s) from their participation in the study?
 No.
 Yes.
 Please explain: The participants expressed interest in enhanced understanding about care of older persons who reside in the long-term care section of nursing homes.
3. If any recent literature has been published or presented by you or others since the last IRB review, has it demonstrated a significant impact on the conduct of the study or the well-being of subjects?
 N/A. There has not been any recent literature published or presented since the last IRB review.
 No.
 Yes. Attach a copy or explain: _____
4. Have there been any audits from federal agencies conducted since the last IRB review that identified unanticipated problems involving risks to subjects or others or noncompliance?
 No.
 Yes. Attach the report(s).
5. Do you believe the risk/benefit ratio has changed based on all of the information provided on this form and any attachments?
 No.
 Yes. Explain: _____

SECTION VII: CO-INVESTIGATOR UPDATE

- This submission does NOT include additions or removals to the Investigator List. *Proceed to section VIII.*
 This submission includes additions or removals to the Investigator List. The updated Investigator List is attached.

The following investigators are being added to the current Investigator List:

The following investigators are being removed from the Investigator List and will no longer be participating in this research:

SECTION VIII: REQUIRED ATTACHMENTS

All current study documents must be included with your continuing review submission. Please check the appropriate boxes as they apply to your study.

- | | |
|--|---|
| <input checked="" type="checkbox"/> Assent, dated: <u>7/9/12</u>
Number of assent documents: _____ | <input checked="" type="checkbox"/> Investigator List, dated: <u>7/9/12</u> |
| <input checked="" type="checkbox"/> Authorization, dated: _____
Number of authorizations: _____ | <input type="checkbox"/> Medical Device Form, dated: _____ |
| <input type="checkbox"/> Clinical Investigator's Brochure, dated: _____ | <input checked="" type="checkbox"/> Protocol, dated: <u>7/9/12</u> |
| <input type="checkbox"/> Drug or Biological Products Form, dated: _____ | <input type="checkbox"/> Recruitment materials (please list and date): _____ |
| <input type="checkbox"/> Expedited Research Checklist, dated: _____ | <input checked="" type="checkbox"/> Request form(s) for vulnerable population(s) (please list and date); <u>Cog Imp, 7/9/12</u> |
| <input checked="" type="checkbox"/> HIPAA & Recruitment Checklist, dated: <u>7/9/12</u> | <input type="checkbox"/> Surveys, questionnaires (please list and date): _____ |
| <input checked="" type="checkbox"/> Informed Consent, dated: <u>7/9/12</u>
Number of consent documents: 2: (<u>Informed Consent and Delegation of Authority to Consent Form</u>). | <input checked="" type="checkbox"/> Summary Safeguard Statement or HUD Form, dated: <u>7/9/12</u> |
| | <input checked="" type="checkbox"/> Study Information Sheet |
| | <input type="checkbox"/> Test Articles Supplement, dated: _____ |
| | <input type="checkbox"/> Other (please list and date): _____ |

Include the following documents, as applicable:

- Publications, if you answered YES to VI.3. above
- Audit reports, if you answered YES to VI.4 above
- Summaries, if you indicated in Section V that summaries are attached
- DSMB report, if the study includes a DSMB and you are submitting the most recent DSMB report
- Interim findings, if there are any to report
- Multi-center trial reports, if there are any available

NOTES:

- No changes to previously approved study documents are allowed at the time of continuing review unless requested by the IRB.
- Incomplete submissions will result in a processing delay, which could result in study expiration.
- **VA Requirements:** For studies conducted at the VA, utilizing VA funding or VA patients, you must provide a copy of the approved continuing review form to the VA Research Service office.

SECTION IX: INVESTIGATOR STATEMENT OF COMPLIANCE

By submitting this form, the Principal Investigator assures that all information provided is accurate. He/she assures that procedures performed under this project will be conducted in strict accordance with federal regulations and Indiana University policies and procedures that govern research involving human subjects. He/she acknowledges that he/she has the resources required to conduct research in a way that will protect the rights and welfare of participants, and that he/she will employ sound study design which minimizes risks to subjects. He/she agrees to submit *any* change to the project (e.g. change in principal investigator, research methodology, subject recruitment procedures, etc.) to the Board in the form of an amendment for IRB approval prior to implementation.

SECTION X: IRB APPROVAL

For IU Human Subjects Office Use Only

Type of review: Full Board
 Expedited, Category: _____ Approved for a period of: one (1) year two (2) years

STATUS OF STUDY: ONGOING - Open to Enrollment

This continuing review has been reviewed and approved as meeting the criteria for IRB approval as outlined in 45 CFR 46.111(a) by the Indiana University IRB. Based on the criteria for determining the frequency of continuing review and the level of risk, this study will expire on: 7/11/14. If the study is not re-approved prior to that date all research activities must cease on that date, including enrollment of new subjects, intervention/interaction with current participants, and analysis of identified data.

Authorized IRB Signature: [Signature] IRB Approval Date: 7/12/13 *

Printed Name of IRB Member: _____

*Reviewed & approved at July 12, 2013 IRB-01 meeting. Signed electronically rather than with ink. Printed and signed 7/29/13. bj

For IU Human Subjects Office use only.

Recorded in the Minutes of: _____

**APPENDIX C. MONTREAL COGNITIVE ASSESSMENT (MOCA) INSTRUMENT
AND PERMISSION FOR USE**

MONTREAL COGNITIVE ASSESSMENT (MOCA)

NAME: _____
Education: _____ Date of birth: _____
Sex: _____ DATE: _____

VISUOSPATIAL / EXECUTIVE		Copy cube					Draw CLOCK (Ten past eleven) (3 points)			POINTS			
							<input type="checkbox"/> Contour <input type="checkbox"/> Numbers <input type="checkbox"/> Hands				___/5		
NAMING													
								<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>			___/3		
MEMORY		Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.					FACE	VELVET	CHURCH	DAISY	RED	No points	
		1st trial											
		2nd trial											
ATTENTION		Read list of digits (1 digit/ sec.). Subject has to repeat them in the forward order					[] 2 1 8 5 4					___/2	
		Subject has to repeat them in the backward order					[] 7 4 2						
		Read list of letters. The subject must tap with his hand at each letter A. No points if ≥ 2 errors					[] FBACMNAAJKLBAFAKDEAAAJAMOF AAB					___/1	
		Serial 7 subtraction starting at 100					[] 93	[] 86	[] 79	[] 72	[] 65	___/3	
							4 or 5 correct subtractions: 3 pts , 2 or 3 correct: 2 pts , 1 correct: 1 pt , 0 correct: 0 pt						
LANGUAGE		Repeat : I only know that John is the one to help today. [] The cat always hid under the couch when dogs were in the room. []										___/2	
		Fluency / Name maximum number of words in one minute that begin with the letter F					[] _____ (N ≥ 11 words)					___/1	
ABSTRACTION		Similarity between e.g. banana - orange = fruit					[] train - bicycle	[] watch - ruler				___/2	
DELAYED RECALL		Has to recall words WITH NO CUE					FACE	VELVET	CHURCH	DAISY	RED	Points for UNCUED recall only	___/5
							[]	[]	[]	[]	[]		
Optional		Category cue											
		Multiple choice cue											
ORIENTATION		[] Date					[] Month	[] Year	[] Day	[] Place	[] City	___/6	
		© Z.Nasreddine MD Version 7.1					www.mocatest.org			Normal ≥ 26 / 30		TOTAL	___/30
		Administered by: _____										Add 1 point if ≤ 12 yr edu	

RE: MoCa Test

Page 2 of 3

260-481-6015
Fax: 260-481-5767
reimern@ipfw.edu

>>> Info-MoCA 06/10/10 3:20 PM >>>

Dear Nila,

You are welcome to use the MoCA in your study as described below with no further permission requirements if it is not industry funded.

Shall any industry funding become available, a licencing agreement to use the MoCA will be required.

All the best,

Ziad Nasreddine MD FRCP(C)
Assistant Clinical Professor
Université de Sherbrooke and McGill
University Center for Diagnosis and Research on Alzheimer's disease
4896 Taschereau Blvd, suite 250, Greenfield Park, J4V 2J2, Québec,

info@mocatetest.org Phone: 450-672-7766 Fax: 450-672-1443
www.mocatetest.org

www.mocatetest.org
www.NilaaReimer

From: reimern@ipfw.edu Nila Reimer [mailto:reimern@ipfjuinu]
Sent: 10 juiiinfo@mocatetest.org
To: info@mocatetest.MoCa
Subject: RE: MoCa Test

Hello,

I appreciate your timely response. This will be a qualitative descriptive study with approximately 15-20 residents who will receive a cognitive assessment prior to their interview with the research MOCA herefore, the MOCA will be administered approximately 15-20 times in total for this study. There is no funding that supports this NilayReimer

Thank yNila

NReimerimer

Nila Reimer, MS, RN, Doctoral Candidate
Continuing Lecturer, Acting Director of Undergraduate Programs NursinUniversity-Purdue
Indiana University-Purdue University Fort Wayne
2101 E. Coliseum Blvd.
Fort Wayne, IN. 46805
260-481-6015
reimern@ipfw.edu7
reiInfo-MoCA.edu

>>> Info-MoCA 06/10/10Nila2 PM >>>

<https://gwwa.ipfw.edu/gw/webacc?User.context=ed7422a278bf5e1cf1f68f5d406e68d12a5...> 6/11/2010

APPENDIX D. NURSING HOME LETTERS OF CONSENT FOR PARTICIPATION
IN STUDY



January 12, 2012

To: Indiana University Institutional Review Boards

The Towne House Retirement Center agrees to cooperate with Nila Reimer, PhD in Nursing Science student at Indiana University School of Nursing, in conducting a qualitative study titled, "Things That matter to Residents in Nursing Homes and the Nursing Implications." We understand that this qualitative study will involve Ms. Reimer's interviewing residents who live in our nursing home facility. We have no additional Internal review Board approval that will be required.

Ms. Reimer has informed us that the interviews may begin in January 2012 and the study will conclude by August 2013.

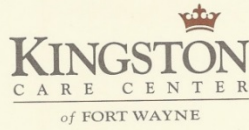
Sincerely,


Amy L. Scheffer, RN

Director of Nursing

The Towne House Retirement Community

2209 St. Joe Center Road ❖ Fort Wayne, IN 46825
(260) 483.3116 ❖ Fax (260) 969.8025
www.townehouse.org
Nationally Accredited by the Continuing Care Accreditation Commission



January 12, 2012

To: Indiana University Institutional Review Boards


Kingston Care Center will be cooperating with Nila Reimer, PhD in Nursing Science student at Indiana University School of Nursing, in conducting a qualitative study titled, "Things That Matter to Residents in Nursing Homes and the Nursing Implications." We understand that this qualitative study will involve Ms. Reimer's interviewing residents who live in our nursing home facility. We have no additional Internal Review Board approval that will be required.

Ms. Reimer has informed us that the interviews may begin in January 2012 and the study will conclude by August 2013.

Sincerely,



1010 W. Washington Center Road / Ft. Wayne, IN 46825
Tel: 260-489-2552 Fax: 260-487-9912

 www.kingstonhealthcare.com



SAINT ANNE HOME *and*
RETIREMENT COMMUNITY

January 13, 2012


To: Indiana University Institutional Review Boards

Saint Anne Home agrees to cooperate with Nila Reimer, PhD in Nursing Science student at Indiana University School of Nursing, in conducting a qualitative study titled, "Things That Matter to Residents in Nursing Homes and the Nursing Implications". We understand that this qualitative study will involve Ms. Reimer interviewing residents who live in our nursing home facility. We have no additional Internal Review Board approval that will be required.

Ms. Reimer has informed us that the interviews may begin in January 2012, and the study will conclude by August 2013.

Sincerely,

SAINT ANNE HOME & RETIREMENT COMMUNITY


Corrina Rees, RN
Director of Nursing

1900 Randallia Drive
Fort Wayne, Indiana 46805
260.484.5555

www.saintannehome.com

a place to call home.

APPENDIX E. INFORMED CONSENT

IRB Study # 1009001703

INDIANA UNIVERSITY INFORMED CONSENT STATEMENT FOR

Things That Matter to Residents in Nursing Homes and the Nursing Care Implications

You are invited to participate in a research study about things that matter to residents in nursing homes. You are selected as a possible subject because you reside in the long-term, intermediate care unit. We ask that you read this form and ask any questions you may have before agreeing to be in the study. If you are a legal guardian signing this form on behalf of a subject, where it says "you" please read "the subject."

The study is being conducted by Nila Reimer, PhD in Nursing Science student and Sara Horton-Deutsch, PhD, RN from the Indiana University School of Nursing.

STUDY PURPOSE

The purpose of this study is to gain understanding about things that residents state matter to them while living in nursing homes. Investigating things that matter to residents will help nursing home caregivers to understand what may be important to include in care of residents while living in nursing homes. In addition, we will look at things that may not matter to residents during their care in nursing homes. You will have an opportunity to share things that matter to you that may be included in your care in the nursing home.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to participate, you will be one of up to ten (10) subjects who will be participating in this research.

PROCEDURES FOR THE STUDY:

If you agree to be in the study, you will do the following things:

- Agree to answer questions in a cognitive assessment called the Montreal Cognitive Assessment that the researcher will present to you. The Montreal Cognitive Assessment will take about ten minutes for you to complete. The cognitive assessment must reflect a score that indicates no or mild cognitive impairment in order for you to participate in the study.
- Participate in an interview in person with the researcher that will take approximately 60 minutes.
- Agree to meet for a second interview with the researcher to go over the information from the first interview to be sure that the information is correct.
- Participate in the interview in an area that you feel is private and comfortable in the nursing home.
- Agree that the conversation may be audio recorded for assuring accuracy of the information that you will be sharing with the researcher.
- Permit the interview to be typed on paper by the researcher, or a research assistant or trained typist. All personal information and your name will be changed so that your identity is protected. The tape or digital recording will be destroyed after the interview has been typed and rechecked for accuracy.
- Agree that after the study is completed, the researcher may share the study results with the residents and staff members at the nursing home where you reside. Your name and cognitive assessment information will be kept private and will not be shared with any of the other residents or staff members.
- Agree that after the study is completed, the researcher may share the study results with nurses and nursing students in other nursing care areas such as hospitals or colleges. Your name and cognitive assessment information will be kept private and will not be shared with any of the nurses or nursing students.

- Agree that the researcher may publish the study results in journals or books and share the study results at presentations or conferences. Your name, cognitive assessment information, and the name of the nursing home will not be provided in journals or books or at any conferences.

RISKS OF TAKING PART IN THE STUDY:

While on the study, the risks of your describing things that matter in the nursing home are:

- Potential anxiety or stress for you because of your reflecting on things that matter to you in the nursing home.
- The possibility of your becoming tired during the interview. However, you may refuse to answer any questions, take breaks as you desire for the amount of time that you wish to have, or stop participating in the study at any time during the interview without penalty.
- Potential loss of confidentiality; however, the researcher will protect your privacy and confidentiality as much as possible before, during, and after the interview. In addition, the researcher will protect your privacy and confidentiality when she obtains the cognitive assessment information from you, and analyzes and stores the information from your interview.
- Potential interference with your care in the nursing home; however, the interview will be scheduled so as not to interfere with any of your ongoing therapy or regimens and will be scheduled at your discretion.

BENEFITS OF TAKING PART IN THE STUDY:

The benefits of participating in the study are that you may describe things that matter to you in the nursing home that may provide information to improve nursing care of residents and nursing education. Your description of experiences in the nursing home will be heard and may lead to better care for residents in nursing homes.

ALTERNATIVES TO TAKING PART IN THE STUDY:

Instead of being in the study, you have the option of choosing not to participate.

CONFIDENTIALITY

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published. The researcher will try to keep your personal information confidential; however, the researcher cannot guarantee absolute confidentiality. Ways that the researcher will try to protect your confidentiality include the following:

1. Before, during, and after the interview, the researcher will not keep your name or birth date on any information that is obtained from you. Your cognitive assessment information will not have your name or your birth date on it. The researcher will not share your agreement to participate or not to participate in the interview for the study with nursing staff members or other residents. Your informed consent and authorization to obtain protected health information, which will be your cognitive assessment information, will be obtained from you before we begin the study.
2. During the interview, the researcher will not share your conversation with any of the staff members or residents at the nursing home. The interview will take place in a private place that you choose in the nursing home. Anything that you say during the interview will be kept private between you and the researcher. The interview data will be stored in databases that will be

locked in a cabinet in the co-investigator's office and/or accessed with a security code or password.

3. After the interview, the researcher will keep the taped conversation between you and the researcher available only to the researcher or her research team members. The research team members are person(s) who may help with typing and/or reviewing the information. The researcher will not report your name or the name of the nursing home when she shares information from your conversation with the person(s) who may help with typing and/or reviewing the information. The researcher will not share your name or cognitive assessment information, and the name of the nursing home, in any reports in which the study may be published. Your name, cognitive assessment information, and the name of the nursing home will not be shared with any other persons viewing the study results. Also, the researcher will destroy the audio tape recordings after the interview information has been typed.

4. After the study is completed, the researcher will review all of the residents' interviews, including your interview, and look at things that matter described by each of the residents who will be in the study. The researcher will share these important things that matter with other nurses, including the nursing staff members here at the nursing home, nursing students, and other nurses who are interested in caring for residents in nursing homes. Your name and any other medical record information and the name of the nursing home will not be shared with any nursing staff members, others nurses, or nursing students.

5. During the entire study process, organizations, such as the Indiana University Institutional Review Board, consists of members who assure proper research methods. These members or their representatives may check your research record. Also, state or federal agencies, which could be the Office for Human Research Protections (OHRP), may check your research records. Your personal information may be disclosed if required by law.

COSTS

There will be no costs to you for participating in the study.

PAYMENT

You will receive a token of appreciation for taking part in this study. After completing the interviews, a \$25 gift card will be presented to you for appreciation of your time and willingness to participate in the interview.

COMPENSATION FOR INJURY

In the event of physical injury resulting from your participation in this research, necessary medical treatment will be provided to you and billed as part of your medical expenses. Costs not covered by your health care insurer will be your responsibility. Also, it is your responsibility to determine the extent of your health care coverage. There is no program in place for other monetary compensation for such injuries. However, you are not giving up any legal rights or benefits to which you are otherwise entitled. If you are participating in research which is not conducted at a medical facility, you will be responsible for seeking medical care and for the expenses associated with any care received.

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study or a research-related injury, contact the researcher Sara Horton-Deutsch, PhD, RN at 317-274-2425. If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949.

In the event of an emergency, you may contact Sara Horton-Deutsch at 317-274-2425.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458 or [for Indianapolis] or (812) 856-4242 [for Bloomington] or (800) 696-2949.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with the nursing home where you reside.

Your participation may be terminated by the investigator without regard to your consent in the following circumstance: If you do not agree to complete the interview or you should become unable to complete the interviews. You will be informed by the researcher that your participation may be terminated within ten days after the last interview.

SUBJECT'S CONSENT

In consideration of all of the above, I give my consent to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree to take part in this study.

Subject's Printed Name: _____

Subject's Signature: _____ Date: _____
(must be dated by the subject)

On behalf of the subject, I give my consent for the subject to participate in this research study.

Printed Name of Legally Authorized Representative: _____

Signature of Legally Authorized Representative: _____ Date: _____

Printed Name of Person Obtaining Consent: _____

Signature of Person Obtaining Consent: _____ Date: _____

For IRB Office Use ONLY
IRB Approval Date: July 12, 2013
Expiration Date: July 11, 2014

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CURRICULUM VITAE

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Education

Doctor of Philosophy (Nursing Science). Indiana University (Indiana University–Purdue University Indianapolis). 2014.

Master of Science (Nursing Administration). Purdue University (Indiana University–Purdue University Fort Wayne). 2003.

Honors, Awards, Fellowships

Indiana League for Nursing Scholarship. (2012, June).

Indiana University School of Nursing. (2010, November). Selected for poster competition at the 2011 Midwest Nursing Research Society Conference.

Indiana University–Purdue University Indianapolis Faculty Development. (2010, October). Graham Faculty Scholarship.

American Association of Colleges of Nursing / Hartford Institute for Geriatric Nursing Education Consortium grant. (2009, January).

Indiana University–Purdue University Fort Wayne. (2006, February). Gerontological Nursing course development grant.

Research and Training Experience

Reimer, N. (2013). *Things that matter to residents in nursing homes and the nursing care Implications* (Unpublished doctoral dissertation). Indiana University–Purdue University School of Nursing, Indianapolis, IN.

Qualitative analysis 1: Empirical/analytical methods. (2010, June). Carolina Summer Research Institutes and Courses 2010, Chapel Hill, NC.

Institutes for Heideggerian Hermeneutical Phenomenology Methodologies. (2008, June). Indiana University–Purdue University Indianapolis, Indianapolis, IN.

Geriatric Nursing Education Consortium Institute. (2009, April). American Association of Colleges of Nursing & Hartford Institute for Geriatric Nursing. San Diego, CA.

Reimer, N. (2003). *An examination of the effects of exercise on quality of life for Elderly residents* (Unpublished master's thesis). Indiana University–Purdue University Fort Wayne, Fort Wayne, IN.

Professional Experience

Indiana University–Purdue University Fort Wayne. (June 2004–present). Continuing Lecturer. Fort Wayne, IN.

The Oaks–Parkview Health System Long-Term Care. (March 2001–June 2004). Director of Long-term Care. Columbia City, IN.

Parkview Whitley Hospital. (2008–present). Trustee/Board Member. Columbia City, IN.

Parkview Whitley. (2009–2013). Chair of Long-Term Care Task Force. Columbia City, IN.

Parkview Whitley Hospital. (2010–present). Vice-Chair for Board of Quality Committee. Columbia City, IN.

Healthy Cities Inc. (2008–2010). Planning Committee Chair. Fort Wayne, IN.

Conferences Attended

Hear the voice: Honor the choice [Webinar]. Pioneer Network’s 13th annual conference. Retrieved from <http://www.pioneernetwork.net/Data/Documents/2013Conference/PioneerNetworkProgram2013.pdf>.

Sixth Annual Midwest Geriatric Nursing Education Alliance Meeting. (2013). University of Minnesota School of Nursing, Minneapolis, IN.

The transformational power of nursing leadership. (2012) Student Spectacular, Indiana University–Purdue University Fort Wayne, Fort Wayne, IN.

Why bust paradigms: Well-being strategies–Reframing policies and procedures for person-directed care [Web seminar]. (2012). Retrieved from <http://archive.constantcontact.com/fs022/1101511475155/archive/1110045476347.html>.

Flipped, blended & stirred: “Mixing it up” with learner-centered teaching strategies. (2012). Fall Teaching Conference, Indiana University–Purdue University Fort Wayne, Fort Wayne, IN.

Critical thinking across the curriculum. (2012). The Spring Teaching Conference, Indiana University–Purdue University Fort Wayne, Fort Wayne, IN.

Bridging the gap: Teaching under-prepared students. (2012). Fort Wayne Teaching Conference, Indiana University–Purdue University Fort Wayne, Fort Wayne, IN.

Indiana: The forum of state nursing workforce centers: Taking the long view: Visions of the future. (2012). Hendricks Regional Health Symposium, Indianapolis, IN.

- Interprofessional Education: Successful Implementation Strategies.* (2012). Indiana League for Nursing Symposium, Indianapolis, IN.
- Teamworking and appreciative inquiry.* (2012). Nursing Department Faculty Meeting. Indiana University–Purdue University Fort Wayne, Fort Wayne, IN.
- Meeting at the crossroads: Pioneer Network's 10th annual conference.* (2010). Indianapolis, IN.
- Nursing research: Bench to bedside.* (2010). Midwest Nursing Research Society Conference, Kansas City, MO.
- World café' education.* (2011). National Council State Boards of Nursing Meeting, Chicago, IL.
- Leadership in nursing.* (2011). Leadership in Nursing Education, Parkview Health Systems. Fort Wayne, IN.
- Eliminating preventable harm.* (2011). Second Annual Indiana Patient Safety Summit, Indianapolis, IN.
- Residents' descriptions of meaningful experiences in nursing homes.* (2011). Poster session, Midwest Nursing Research Society, Columbus, OH.
- The journey through nursing doctoral education: An inside story.* (2010). Paper presentation, Student Spectacular, Indiana University–Purdue University, Fort Wayne, Fort Wayne, IN.
- Introduction to the QSEN competencies* [Webinar]. (2010). Elsevier Faculty Development and Training, retrieved from <https://elsevier.webex.com>.
- Meeting at the crossroads: Pioneer Network's 10th annual conference.* (2010). Pioneer Network and Picker Institute, Indianapolis, IN.
- A Heideggerian Hermeneutic Phenomenological Approach to Understanding Residents' Perceptions of Meaningful Care in Nursing Homes.* (2010). Poster session, The University of Toledo, Toledo, OH.
- National League for Nursing NLNAC Self-Study Forum.* (2010). National League for Nursing Accrediting Commission, Chicago, IL.
- Enhancing learning through the scholarship of teaching and learning.* (2009). Indiana University–Purdue University Fort Wayne Symposium, Fort Wayne, IN.

A Hermeneutical approach: Finding the personhood of residents in nursing homes. (2009). Indiana University–Purdue University Fort Wayne Nursing Program Symposium, Fort Wayne, IN.

Early instrument development for measuring long-term care residents' perceptions of nursing caregiver therapeutic relationships. (2008). Center for Excellence in Teaching (CELT) Symposium, Indiana University–Purdue University Fort Wayne, Fort Wayne, IN.

Evaluation of the aging process and exercise. (2008). Poster session, University of Toledo Nursing Research Conference, University of Toledo, Toledo, OH.

An examination of the effects of exercise on quality of life of elderly residents. (2003). Symposium, 4th U.S.—Russian Nursing Conference, St. Petersburg, Russia.

Publications

Reimer, N. (2009). The journey through nursing doctoral education: An inside story. *Transformative Dialogues: Teaching and Learning Journal*, 3(2), 1–7.