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**“Coming To Terms”: A Grounded Theory of Dementia Caregivers’  
Journeys and Expectations of Care**

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**“Coming To Terms”: A Grounded Theory of Dementia Caregivers’  
Journeys and Expectations of Care**

**by**

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**Dissertation**

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## **Dedication**

This dissertation is dedicated to the memory of my parents, Lawrence and Elizabeth Mistic and my grandfather, Luis Antonio Quinones, who instilled in me that education was not just preparation for life, but education was life. The dissertation is also dedicated to my great friend Tobin A. Sparling, who provided emotional support and acted as a sounding board.

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# **“Coming To Terms”: A Grounded Theory of Dementia Caregivers’ Journeys and Expectations of Care**

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**Abstract:** “Coming to Terms” presents the subjective narratives of family members about what constitutes quality long term care (LTC) for loved ones with dementia. It uses those narratives to develop a grounded theory of shared meanings of dementia care that reflects the basic social process by which family members formulate their initial expectations of care delivered in LTC settings.

Family members transition through a five-stage process when dementia affects a loved one. As they move through these stages, the family members process the realities of dementia and dementia care, grapple with the decision to place their loved one in a LTC facility, and, ultimately, formulate expectations of the care they want the LTC facility to provide. In essence, family members expect the LTC facility to (1) fulfill their loved one’s basic needs, (2) provide pleasant surroundings, (3) ensure a competent staff, (4) ensure a caring staff, (5) facilitate communication, and (6) practice timely institutional responsiveness. The family members’ expectations not only play a critical role in the initial evaluation of LTC facilities but are also used subsequently to measure the effectiveness of the LTC facility in which the loved one has actually been placed.

Although the expectations of care described in this study are consistent with the findings of prior studies of expectations of care in other contexts, “Coming to Terms” breaks new ground by illustrating the transitional process through which family members’ expectations of dementia care are germinated, tested, refined, and fully formulated. Rich, descriptive detail informed these results and the participants are acknowledged and appreciated.

The findings of this study can help LTC facilities better understand the issues and concerns of the families whom they serve and aid in the development of LTC policies and procedures that foster greater consumer satisfaction and peace of mind.

## Table of Contents

Vita.....	x
List of Tables .....	xii
List of Figures .....	xiii
Chapter One Introduction to the Study .....	1
Introduction and Specific Aims .....	1
Background and Significance .....	3
Introduction to the Method .....	6
<i>Design</i> .....	6
<i>Sample</i> .....	7
<i>Data Collection</i> .....	8
<i>Data Analysis Procedures</i> .....	9
<i>Rigor</i> .....	9
Sensitizing Conceptual Orientation .....	10
Assumptions of the Investigator .....	12
Limitations .....	13
Summary .....	13
Chapter Two Review of the Literature .....	15
Introduction .....	15
Historical and Legal Perspectives: NH Standards and Regulations .....	16
Expectations of Quality Care: Links to Patient Satisfaction and Outcomes .....	20
Expectations of Quality Care: Residents, Patients, and Family Members .....	22
Expectations of Care: Perspectives of Family Caregivers .....	24
Transition Experiences and Life Events .....	28
Summary .....	35

Chapter Three Methodology .....	37
Introduction .....	37
Methodology .....	38
<i>Design</i> .....	38
<i>Sensitizing Orientation for the Study</i> .....	40
<i>Sampling Model and Procedures</i> .....	41
<i>Protection of Human Subjects</i> .....	43
<i>Data Collection</i> .....	45
<i>Data Analysis Procedures</i> .....	46
<i>Rigor</i> .....	50
Summary .....	53
Chapter Four Findings .....	55
Introduction .....	55
Description of the Sample of Participants .....	58
Central Findings: Emergent Theory, Social Process and Expectations .....	60
Detailed Examination of the Stages and Behavioral Phenomena .....	63
<i>Stage 1: Transitions to Caregiver Role</i> .....	63
<i>Stage 2: Takes on Caregiver Role</i> .....	66
<i>Stage 3: Relinquishes Caregiver Role</i> .....	70
<i>Stage 4: Selects and Evaluates a LTC Facility</i> .....	73
<i>Expectations of Patient Care: Fulfilling Basic Needs</i> .....	74
<i>Providing Nutrition</i> .....	74
<i>Helping with Personal Hygiene</i> .....	75
<i>Assisting with Toileting Activities</i> .....	76
<i>Making Sure Loved one Takes Their Medications</i> .....	77
<i>Making sure Loved one Participates in Activities</i> .....	77
<i>Expectation of Pleasant Surroundings</i> .....	78
<i>Expectation of Competent and Knowledgeable Staff</i> .....	80
<i>Expectation of Caring Staff</i> .....	81
<i>Expectation of Communication</i> .....	82



<i>Expectation of Institutional Responsiveness</i> .....	84
<i>Stage 5: Accepting LTC Status</i> .....	86
Summary .....	89
Chapter Five Discussions, Conclusions and Recommendations .....	91
Introduction.....	91
Discussion of the Historical Significance of the Study .....	92
Significance of the Findings in Relation to Other Studies .....	94
<i>Expectations of Care From Perspective of Patient (Consumer)</i> .....	94
<i>Expectations of Care From Perspective of Patient and Caregiver</i> ....	98
<i>Expectations of Care From Perspective of Caregiver</i> .....	100
<i>Transition Model Comparison</i> .....	104
Significance of Findings for Nursing.....	106
Recommendations for Future Research .....	108
Limited Applications of Study Findings .....	109
Conclusions.....	109
Appendix A Subject Consent form .....	111
Appendix B Bio-Demographic Data Sheet.....	116
Appendix C Interview Guide.....	118
Appendix D Recruitment Letter.....	120
Appendix E Recruitment Flyer .....	122
Appendix F Code Book I .....	124
Appendix G Code Book II (A).....	126
Appendix H Code Book II (B).....	128
References.....	133

## **Vita**

### **Michael Lawrence Mistic**

Michael Mistic was born in Washington, D.C. on August 12, 1949 to Lawrence and Elizabeth Mistic. He has two daughters, Victoria and Julianna, and two grandchildren, Matthew and Madison.

Mistic has been a registered nurse since 1971 and a family nurse practitioner since 1997. In June, 1977, he began working as a nurse at the Veterans Administration Medical Center in Little Rock, Arkansas. He has since held clinical and educational positions of increasing responsibility at the Veterans Administration Medical Centers in Durham, North Carolina; Columbia, Missouri; and Houston, Texas, where he currently manages a 30 - bed unit in long-term care.

Mistic has taught nursing as an adjunct faculty member at Houston Community College, Texas Woman's University, Houston Baptist University, and The University of Texas Medical Branch in Galveston, Texas. He has also mentored nursing students enrolled in distance learning programs offered by Ball State University in Muncie, Indiana and Jacksonville University in Jacksonville, Florida.

Mistic spent over thirty-three years in the Army National Guard and is a veteran of Desert Shield and Desert Storm. He retired in 2005 at the rank of Lieutenant Colonel, having held such leadership positions as chief nurse, commander, and executive officer. In 2002 Mistic was inducted into the Order of Military Medical Merit, a U.S. Army award recognizing those who have made significant, exemplary contributions to the United States Army Medical Department. In 2007, the Texas Army National Guard awarded him its Lone Star Distinguished Service Medal, which recognizes significant, exemplary service in the Military Forces of Texas.

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## **List of Tables**

Table 4.1: Demographics of Relatives (Loved ones) with Dementia.....	56
Table 4.2: Behavioral Phenomena That Inform Expectations .....	57
Table 4.3: Dementia Care Expectations of Family Members .....	57
Table 4.4: Family Member (Decision-Maker) Bio-demographic Summary .....	60
Table 4.5: Demographics of Relatives (Loved ones) with Dementia.....	60

## **List of Figures**

Figure 1.1: Nicholson's Transition Cycle of Change .....	11
Figure 4.1: Coming To Terms: Stages in Caregiver Transitions and Behavioral Phenomena That Inform Expectations .....	64

## **CHAPTER ONE**

### **INTRODUCTION TO THE STUDY**

#### **Introduction and Specific Aims**

As the proportion of elderly persons living in the United States increases over the next several decades, the incidence of dementia will rise sharply (National Institute on Aging [NIA], 2006). Without effective prevention strategies and treatment interventions, this devastating neurodegenerative disease will continue to impair more and more victims by robbing them of short and long-term memories and important cognitive and functional abilities (Hebert et al., 2003; Krishnan et al., 2005; Wimo et al., 2003). Demands for dementia care services in long-term care (LTC) settings are also expected to grow, thereby straining the already short-staffed and under-prepared health care system that continues to suffer poor quality ratings and multiple reports of deficiencies.

Growing demands for LTC services that deliver quality dementia care will parallel predicted population trends. Consumers in the baby boomer generation are expected to pressure the LTC industry for higher standards and more services than those currently being offered. However, the LTC industry has been slow to prepare to meet new challenges and has done little to seek input from consumers. Voices of consumers are noticeably limited in reports of research about LTC demands and preferences, especially those that are relevant to dementia care. There currently are five million Americans who suffer with an Alzheimer's-type of dementia and numbers are expected to triple by 2030 (Alzheimer's Association, 2007).

Development of dementia care standards and quality indicators that include the expectations of consumers is an important goal for both research and practice. Previous research has documented that consumers of all types of LTC services want the assurance that when they move into a nursing facility, or place an elderly parent or spouse there, services provided will be of significant quality (Ryan & Scullion, 2000; Schur & Whitlatch, 2003; White, 2005). Yet current standards and regulations pertinent to LTC

services in general were developed years ago without input from consumers (IOM, 1986). Changing demographics and the rising incidence of disabling illnesses, such as dementia bring to light the urgent need to expand specialty and focused LTC services with input from consumers who are destined to need and use such services.

Numerous studies have been done to address issues of quality care in both general and specialized LTC (Butcher et al., 2001; Clark & King, 2003; Colerick & George, 1986; Grant et al., 2002; Lieberman & Kramer, 1991; Maas et al., 1991); however, still missing from the literature are reports of qualitative descriptive studies that reveal subjective perspectives of consumers about what constitutes quality in LTC. Also missing are reports of any prospective studies that discussed consumers' roles in effectively changing the culture of LTC. The standards, preferences, and expectations of quality care that consumers and their family members hold are important to investigate. Data from such studies will make valuable contributions to policies that regulate the LTC industry and determination of consumer-driven quality indicators that should affect planning, implementing, and evaluating care. The findings of the present study will contribute to knowledge necessary to make consumer-driven changes in the overall culture of LTC. The study will provide descriptive data that can be used in the development of quality indicators for setting standards and measuring outcomes of care.

The Omnibus Reconciliation Act of 1987 (hereafter "Nursing Home Reform Act") announced 12 indicators of quality care for LTC more than 20 years ago. Nevertheless, nursing homes remain under fire for failing to provide care that meets the standards outlined in the law. Evidence of these failures is found in the large numbers of public complaints and family-initiated litigation for wrongful deaths that continue to dominate US court dockets in nearly every state (Frantz, 2004; Intaglialia, 2003; Johnson et al., 2004; Silverman & Rocke, 2002). The two primary concerns the present study's investigator has about rising dissatisfaction with care are based on the facts that: (1) the Nursing Home Reform Act is more than 20 years old and has not been amended to keep pace with changing demographics and needs for specialized care, and (2) the voices of consumers are not visible in the law or in any other regulations set forth by the law. The

impact these omissions have on cited failures in the LTC industry should be addressed by research that can fill the gaps in data and contribute to revising care standards that reflect contemporary consumer demands and future demographic and financial concerns.

Correcting the failures and omissions cited above requires more research with consumers to understand their perspectives of LTC and their expectations of quality dementia care (Iwasiw, 1996; Maas et al., 2004). In response to such needs, grounded theory methodology (GTM) (Glaser & Strauss, 1967) was employed to achieve the following specific aims: (1) to elicit the subjective perspectives of family members about what constitutes quality LTC for loved ones with dementia, and (2) to develop a grounded theory of shared meanings about quality dementia care that reflects the expectations of family members in various stages of providing care and relinquishing care for a loved one with dementia. Guided by the study aims and directed by the procedures inherent in GTM, the following research question was answered: How do family members describe their expectations of dementia care in the LTC setting?

Findings of this study, presented in Chapter Four and discussed in Chapter Five, contribute new knowledge about how consumers, specifically family members of individuals with dementia, formulate expectations of quality dementia care while traversing their own transitions as caregivers. The study findings are expected to guide important cultural and practice changes in the LTC industry that will reflect consumer demands for quality dementia care and to suggest important ways in which LTC facilities can translate the findings into development of educational and relationship-building programs for staff, residents, and members of residents' families. Cultivation of a positive LTC environment where expectations of consumers and providers are shared, valued, and used is expected to improve outcomes for all parties.

### Background and Significance

Problems related to the quality of care in our nation's nursing homes have been apparent since the 1950s and through the 1970s, (Brady, 2001; Majesky et al., 1978; White, 2005; Winzelberg, 2003). Detailed regulatory standards have been developed at



both the federal and state levels to address the perceived ills. Over time, skepticism has arisen regarding the usefulness and application of those regulations and standards. Studies conducted in the 1970s by the former Health Care Financing Administration (HCFA) (now an entity subsumed within the Centers for Medicare and Medicaid) revealed that compliance with regulations and standards varied widely across the LTC industry.

Researchers, consumers, and quality-focused organizations during the early 1980s became concerned that the assessment of LTC quality placed far more emphasis on structure and process than on the resident outcomes (Brady, 2001; Rantz et al., 2000). Donabedian's (1966) classical approaches to the evaluation of patient care led many in the health care services industries to realize that despite his recommendations to examine the influences that structure, process, and outcomes had upon quality of care, more work still needed to be done to further define the critical indicators that are true measures of quality care in LTC (Majesky et al., 1978; Openshaw, 1978; The American Geriatric Society, 2000).

The first organized approach to exposing and reporting issues of quality care in nursing homes came about in 1986 at the request of the U.S. Congress. The Institute of Medicine (IOM) published a study titled "Improving the Quality of Care in Nursing Homes." The study concluded that residents of LTC facilities were being abused, neglected, and given inadequate care (Brady, 2001). Accordingly, the IOM proposed sweeping reforms. These reforms were enacted into law with the passage of the Nursing Home Reform Act as part of the Omnibus Budget Reconciliation Act (OBRA) of 1987. The Nursing Home Reform Act answered the need for definitions of quality care and established the basic guidelines for providing quality care. The Act sought to ensure that residents of LTC facilities would receive quality care that allowed them to achieve or maintain their highest practicable physical, mental, and psychological well-being (Brady, 2001).

The publication of the IOM report in 1986 has caused health care workers and researchers to attempt to clarify what constitutes quality care in LTC and to develop

appropriate indicators of quality care. While structure and process have been the primary criteria used to monitor quality in LTC, researchers have influenced the development of outcome measures over time that are linked to evidenced-based practice trends (Rantz et al., 2000). The Nursing Home Reform Act of 1987 responded to the IOM's report by putting federal standards into place for LTC; nevertheless, nursing, medical, and legal literature suggest that more than one-fourth of all LTC facilities continue to be cited for deficiencies that either cause actual harm to residents or carry potential for serious injury or death (Brady, 2001).

Lost amid issues of regulation and quality are the necessary resources and support structures that warrant quality care. Strong consumer voices must be added now to move the industry forward. Even though the Nursing Home Reform Act of 1987 set forth standards for the LTC industry, the voices of consumers, missing from the original quality indicators, remain silent today. The few studies found in the literature that discuss the perspectives family members have about quality care in LTC have done little to move regulators and the industry itself forward with the tasks of revising standards and practices to include consumers' wants and needs.

Also missing from the literature, including the IOM Report, are reports of family members' expectations of quality dementia care in LTC. This may be due to the fact that dementia was not well understood in the general population at the time of the IOM report and the drafting of the Nursing Home Reform Act. Moreover, tools to accurately diagnose dementia did not emerge until the 1990s (Drachman, 2005). Another fact could also be that the proportion of residents with dementia in nursing homes did not reach a critical mass until the mid-1990s (Mechanic & McAlpine, 2000). While studies of adjustments residents make to living in a nursing home have made their way into the literature (Iwasiw et al., 1996; Iwasiw et al., 2003; Johnson, 1990; Matthiesen, 1989; Nolan & Dellasega, 1999; Train et al., 2005), few studies report responses of family members to the admission of a loved one into a LTC facility. In cases where family members who have delivered 24/7 care to loved ones with dementia, it is important and logical to tap this valuable resource when learning about quality of care expectations.

After all, family caregivers of persons with dementia know first hand what must be done and are or will be the love one's spokesperson as the progression of the disorder further incapacitates the affected person.

Given the growing number of elderly who will develop dementia, the intensive investments family members make to the care of affected individuals and the fact that quality indicators do not reflect views and demands of consumers dealing with dementia, this study's findings contribute to closing the gaps in knowledge. Translated and used appropriately, the findings can stimulate the alignment of expectations on all sides of the LTC service scope. People whose loved ones need placement in a LTC facility want to be assured that their loved one will receive quality care.

The primary finding of this study is the basic social process of "Coming to Terms" which provides a thick and rich glimpse into the shared perspectives of dementia caregivers' journeys and illustrates where and how along their journeys the expectations of quality dementia care emerged. The model of this process and the affirming descriptions from the narratives are presented in Chapter Four.

## Introduction to the Method

### *Design*

This study employed grounded theory methodology (GTM) (Glaser & Strauss, 1967) to achieve the aims and answer the research question. Because little research had been conducted from the perspective of the family member's expectations of quality dementia care in LTC, GTM was the appropriate method of choice (Glaser & Strauss, 1967) to build theory. Grounded theory, the intended outcome of GTM, reveals the basic social process found in the analysis and interpretation of narratives shared by members of the study group with the researcher. While a full description of GTM is provided in Chapter Three, an introduction to this method of discovery is offered here to demonstrate the goodness of fit between the research question and choice of method.

GTM emerged in the late 1960s from the seminal work of two sociologists, Barney Glaser and Anselm Strauss (Glaser & Strauss, 1967). The GTM approach is

designed to explore substantive phenomena rather than abstract concepts (Dey, 1999; Fernandez, 2004). GTM is emic in nature in that it explores phenomena from the perspectives of people who interact with and know the phenomena of interest rather than it seeking potentially hypothetical and biased data and using it to create knowledge (Glaser & Strauss, 1967).

Narrative data, as primary data collected and analyzed in GTM, are subjected to rigorous inductive procedures that allow the researcher to see common and shared perspectives about the phenomena of interest presented in the stories of the study group. In this study, data were collected by the investigator during semi-structured interviews with participants. The narratives or stories told by members of the study group were recorded, transcribed, and analyzed for themes that imparted special meanings about caregiving, quality dementia care, and personal journeys through daily life challenges.

### *Sample*

The sample for this GTM was purposefully recruited as a theoretical sample, deliberately assembled to represent the broadest range of perspectives on the topics related to the aims of this study (Glaser & Strauss, 1967). Participants were recruited throughout the duration of the study until data saturation and redundancy were reached and the demographic descriptions of participants affirmed that the goal of maximum variation was achieved (Lincoln & Guba, 1985). Thirteen participants were enrolled. The sample was comprised of spouses and children who were family caregivers for loved ones with dementia. While all eligibility and enrollment criteria and human subjects protection information are presented in detail in Chapter Three, it is important to mention here that eligible caregivers must have recently placed their loved one in a LTC facility or were about to complete this action.

Administrators and admissions coordinators at three LTC facilities in a major city in the southwest United States participated in sample recruitment by providing inquiring family members with information about the study and how to reach the investigator for details. The collaborating facilities represented private, government-sponsored, and

public sectors of LTC service providers. Varying the types of LTC facilities from which the sample was drawn facilitated access to a multi-ethnic, multi-cultural, and multi-socioeconomic population. As themes and categories of meaning emerged from the ongoing analysis of interview data, purposive, theoretical sampling continued until data saturation and redundancy were reached and the basic social process became transparent (Dey, 1999; Glaser & Strauss, 1967; Lincoln & Guba, 1985; Strauss & Corbin, 1990).

### *Data Collection*

After individuals who expressed interest in the study had all questions answered, those wishing to participate read and signed the informed consent. An appointment for an interview was established at the convenience of each participant and a location of his or her choosing was identified. Using the semi-structured interview guide for this study (Appendix C), interviews were tape-recorded and transcribed by this investigator for ongoing analysis. Study materials were coded with an identification number that had no relationship to the individual's name. All study materials were locked in a file cabinet in the investigator's office. Only the investigator held the key and had access to separately stored legend that linked coded data to the source; necessary in the event that participants needed to be contacted for follow-up or agreed to participate in member checks at a later date.

All participants were asked the same questions during interview sessions. The rules and assumptions of GTM ensure that the findings will represent the family members' expectations and not the expectations of health care professionals, government bodies, and others outside the family. Therefore, an audit trail, methodological notes, member checks, and tests of applicability were used to evaluate the reliability and validity of the study's procedures and findings (Lincoln & Guba, 1985).

Bio-demographic data were collected by the investigator and served to provide a description of the sample (Appendix B). The description of the sample's demographics were important to the strategies put into place to achieve a purposeful, theoretical, and

maximally varied sample. Details about sample recruitment are provided in Chapter Three. The description of the sample of study participants is presented in Chapter Four.

#### *Data Analysis Procedures*

Data were analyzed using iterative interpretation strategies and coding processes outlined by Glaser and Strauss (1967). In GTM, it is during data analysis that hypotheses and themes are generated amongst the narratives to explain patterns of behavior contained in the interview transcripts. In addition to this thematic analysis, a method called constant comparison was used to identify categories of meaning and highlight the emergence of the basic social process that was recognized as “Coming to Terms”. All data analysis methods and procedures are detailed in Chapter Three of this dissertation. Thick and rich description of “Coming to Terms” is presented in Chapter Four.

#### *Rigor*

The trustworthiness or truth value of this study and its findings were examined using the criteria set forth by Lincoln & Guba (1985). Inherent in the process of this evaluation is the appraisal of the study’s scientific rigor that entails determining the integrity of the methods and the investigator who conducted the study. The criteria used in this examination and evaluation were dependability, confirmability, credibility, and transferability (Lincoln & Guba, 1985). Dependability was met by establishing a verifiable audit trail that involved field notes, methodological notes, and the researcher’s personal journal recorded while the study was in progress. Confirmability was met by having another researcher verify that data coding and emergent themes performed and identified by the investigator were consistent with what another researcher would do and find if he or she was the principal investigator for this study. Credibility was established by verifying that participants met eligibility and inclusion criteria and by asking a sub-sample of participants to critique themes and determine that they truly represent what they communicated to the investigator during the interviews. Transferability may be established in the future when the findings may be found appropriate to apply to a similar

population in a similar setting and under similar conditions. These criteria and procedures are discussed in detail in Chapter 3.

### Sensitizing Conceptual Orientation

The sensitizing conceptual orientations in qualitative studies serve to contextualize and delimit the phenomena of interest while placing the current work in perspective related to what is already known and what, how, and why new knowledge is sought. Theory testing is not the objective of qualitative research or this GTM study. However, to guide the researcher and inform the reader about the investigator's assumptions, the following orientation was delineated.

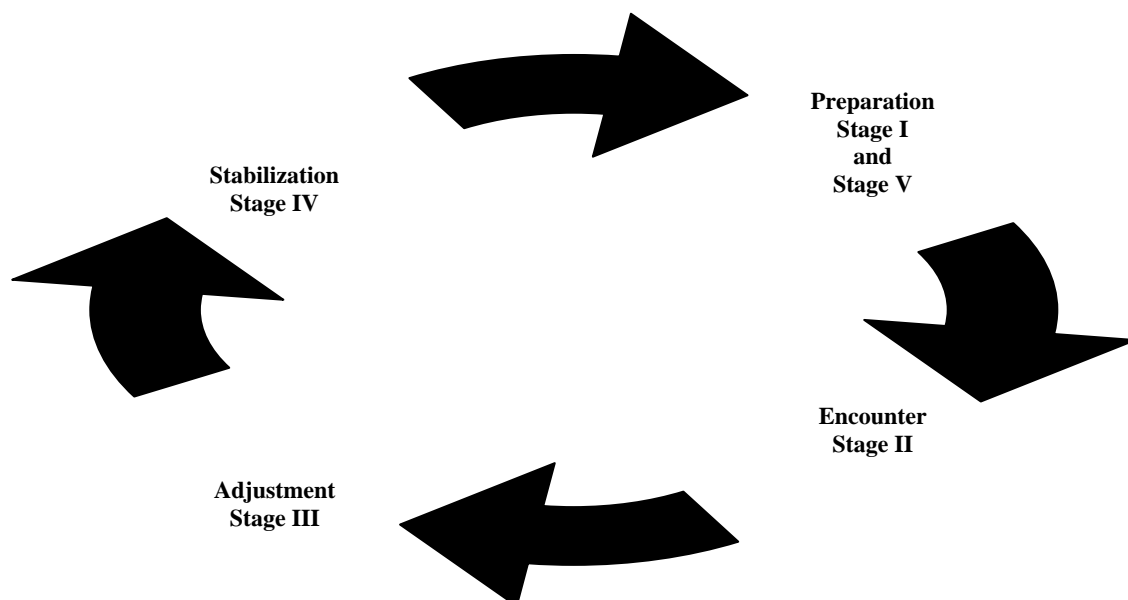
It is widely accepted in the literature that admissions of dementia patients to LTC facilities typically occur under duress, when caregivers and other relatives are exhausted and the patient or resident is experiencing a wide range of emotions, cognitive and functional disabilities, and feelings of abandonment (Chenoweth & Spencer, 1986; Deimling & Poulshock, 1985; Hagan, 2001; Johnson, 1990; Lieberman & Kramer, 1991; Matthiesen, 1989; Smallegan, 1985). For purposes of this study, the real or anticipated admission of a loved one to a LTC facility is recognized and theoretically interpreted as a time of transition.

Schumacher and Meleis (1994) defined transition as, "a passage or movement from one state, condition, or place to another" (p. 119). Using this definition, eligibility criteria were put into place, recruitment strategies were determined, and the investigator affirmed that the situation of having to admit a loved one to LTC after months and years of in-home caregiving qualified as a transition as defined by Chick and Meleis (1986). According to Chick and Meleis, situational transitions include changes in family circumstances and dynamics brought about when a family member leaves the traditional family setting and moves to an institutional setting, like a LTC facility (Iwasiw et al., 1996; Johnson et al., 1992; Young, 1990). Schumacher & Meleis (1994) have purported further that expectations an individual has about events in his or her life are considered components of subjective phenomena that influence that person's transition experiences.

Using the assertions of these theorists, the context, limitations, and design of this GTM study were built. Although the nurse theorists cited above have made major contributions to defining transitions in the context of nursing's metaparadigm, their approaches and interpretations remain loosely constructed until more research can be conducted to add to the knowledge base. Therefore, a model of transitions developed by Nicholson (1990), a non-nurse, was selected to guide the interpretation of this study's findings and to place the findings into the growing body of knowledge of nursing practice and research.

Nicholson (1990) views transitions as cyclical, ongoing, continuous, and dynamic in nature. He defines his four stages of transitions as: (1) preparation, (2) encounter, (3) adjustment, and (4) stabilization (Figure 1.1). Nicholson purports that individuals circumnavigate the transition cycle by recognizing tasks and challenges they encounter, describing pitfalls and problems that await them, and suggesting solutions that come from both internal and external support systems. There is no endpoint in such a cyclical experience, because, as Nicholson explains, "even the most stabilized conditions contain the possibility for future change, and, therefore, embody varying states of readiness for the onset of a new cycle." Indeed, "what happens at one stage exerts a powerful influence over what happens at the next" (Nicholson, 1990, p. 88).

Figure 1.1: Nicholson's Transition Cycle of Change





Critical to this investigator's ability to recruit study participants with wide ranges of experiences with transitions and diverse expectations of quality dementia care is Nicholson's conceptualization of change and Schumacher and Meleis' (1994) conceptualization of interactions between expectations and transitions. Both theoretical positions guided recruitment and sampling strategies, participant selection, interview question development, and bio-demographic queries related to age of the participant, relationship to the person being admitted to the LTC facility, and nature and extent of involvement of the study participant in care of the individual being admitted.

#### Assumptions of the Investigator

Multiple realities exist in any given situation and a representation of what is common among those multiple realities is a goal of qualitative research. However, it is understood that the perspectives of the researcher and the individuals being interviewed will influence the data and findings of the study. To control for researcher bias, this investigator used bracketing (Glaser & Strauss, 1967) and performed evaluations of rigor discussed earlier in the Trustworthiness section of this chapter and presented in detail in Chapter Three.

Qualitative research assumes that all information is context bound. Therefore, all information on family members' transition experiences and expectations of quality care for LTC residents with dementia were considered context bound. It also was assumed that the participants provided an accurate description of their experiences and expectations.

Three basic assumptions of the Nicholson's (1990) transition cycle also influenced this study. It was assumed that his transition cycle was a recursive (cyclical) phenomenon. From that, it was assumed that each informant in the study could possibly be in one or more stages of "Coming to Terms", simultaneously. Following the data, it was revealed that "Coming to Terms" emerged as a disjunctive model (divided into stages) because of the different psychological and behavioral phenomena that participants experienced within and across various stages. The stages are in and of themselves

independent and interdependent, with blurred lines of demarcation. What has become clear in “Coming to Terms” and had already been established in Nicholson’s (1990) work is that stages of transition cycles are interdependent in that “what happens at one stage exerts a powerful influence over what happens at the next stage” (p. 88).

### Limitations

While findings of qualitative studies with small sample sizes are not widely generalizable, they can be transferred to guide replication studies and translated to practice in areas that closely resemble the setting where the original research was conducted. Therefore, since the findings of this study represent the perspectives and experiences of only those who volunteered to participate, it cannot be assumed that such perspectives are widely held in the general population since there is no way to warrant that the sample is representative. Qualitative research is not designed to be representative of any population. Rather, the goal of sampling in qualitative research is to achieve maximum variation on perspectives about a phenomenon within a given population of interest.

Sampling bias can be a factor in qualitative studies. It is possible that the people who participated in the study had greater concerns about quality of dementia care than others. The veracity of the data is also a limitation. The researcher accepts that all information given by the study subjects is true information.

### Summary

The general population is aging and the incidence of dementia will increase proportionately, understanding expectations of quality dementia care in LTC is necessary to bring industry and regulating standards up-to-date and align them with consumer demands. Guided by conceptualizations of expectations and transitions, this grounded theory study aimed to: (1) to elicit the subjective perspectives of family members about what constitutes quality LTC for loved ones with dementia, and (2) to develop a grounded theory of shared meanings about quality dementia care that reflects the

expectations of family members in various stages of relinquishing care for a loved one affected by dementia.

The study results are expected to contribute to the development of consumer-driven indicators of quality dementia care, guide important cultural and practice changes in the LTC industry that reflect consumer demands for quality care, and propose content for future education programs that will bring consumers and providers together in a positive environment that strives for better resident care and outcomes.

## **CHAPTER TWO**

### **REVIEW OF THE LITERATURE**

#### **Introduction**

This chapter will present reviews and critiques of published research reports that address: (1) quality of care issues in long-term care (LTC), (2) family interpretations of dementia care, and (3) consumer participation in developing LTC care standards and indicators of quality care. The studies reported in the chapter serve to establish the body of knowledge available to this investigator about the aspects of LTC that substantially influence quality of care issues such as regulation, consumer demand and satisfaction, financial reimbursement structures, and movements aimed at improving care outcomes and quality of life among LTC residents. The chapter presentation is organized according to sections that will discuss historical and legal perspectives of LTC regulation, results of studies that have explored and described residents' and family members' perspectives of LTC, and the gaps in knowledge that this study's findings are expected to begin to fill.

As mentioned in Chapter One, in the introduction to this study, the nursing home industry remains under fire for failing to provide adequate care to its residents (Frantz, 2004; Intaglialia, 2003; Johnson et al., 2004; Silverman & Rocke, 2002). Consumers of LTC services, typically elderly persons and their family members', want care that is of significant quality (Ryan & Scullion, 2000; Schur & Whitlatch, 2003; White, 2005); however, the literature contains no evidence that residents and family members have been asked to contribute their expectations of LTC to the development and refinement of quality care indicators. Some authors have suggested that the rise in litigation for wrongful deaths and negligence brought by family members against LTC facilities where their loved ones resided have their sources in discontent with care and misunderstandings about what constitutes quality care.

Only rigorous, scientific explorations of family members' expectations of LTC can fill this gap and enable consumers and service providers to jointly construct standards of care that deserve to be called "quality" care standards (Iwasiw, 1996; Maas et al., 2004). LTC services must sensitively and competently meet the needs of individuals affected by dementia because they cannot speak for themselves and rely on family members to be their advocates. In addition, US population statistics and demographics predict that persons who are affected by dementia will comprise between 50% and 80% of the LTC population of residents by the year 2030 (NIA, 2006).

#### Historical and Legal Perspectives: Nursing Home Standards and Regulations

As early as the 1950s and through the 1960s and 1970s, problems relating to the quality of care in the nation's nursing homes escalated (Brady, 2001; Majesky et al., 1978; White, 2005; Winzelberg, 2003). Detailed regulatory standards were developed at both the federal and state levels to address the perceived ills. Over time, skepticism arose regarding the usefulness and application of those standards. Studies conducted by Health Care Financing Administration (HCFA) during the 1970s revealed that compliance with existing regulations varied widely. Also, during the early 1980s, researchers, consumers, and organizations became concerned that quality assessment of LTC placed far more emphasis on structure and process than on the resulting outcomes of care the residents received (Brady, 2001; Rantz et al., 2000). During this same span of time, three classical approaches to patient care evaluation arose. They focused on structure, process, and outcomes (Donabedian, 1966; Majesky et al., 1978; The American Geriatrics Society, 1993). Despite the increasing interest in measuring and evaluating LTC, overtime, Openshaw (1978) pointed out that problems associated with measuring effective care were complicated by the lack of a clear definition of quality care and related indicators (Openshaw, 1978).

Prior to the enactment of Medicare and Medicaid in 1965, oversight of the nursing home industry was the responsibility of each State with minimal federal guidance (Brady, 2001). With Medicare and Medicaid came a dramatic increase in federal funding of

nursing homes. Accompanying these funding programs, health and safety standards for nursing homes that wished to participate were established by the United States Department of Health, Education and Welfare (Brady, 2001). The standards proved so rigorous that only 740 of the more than 6000 nursing home applicants seeking to participate were fully certified (Brady, 2001). What followed was the federal government's decision to abandon the idea of promulgating federal nursing home licensing standards and it returned the full responsibility to the States.

In the 1970s, a highly publicized class action lawsuit, *Smith v. O'Halloran*, 557 F. Supp 289 (D. Col. 1983), provoked the federal government to revisit the need for federalized nursing home regulations (Brady, 2001). In their lawsuit, the plaintiffs challenged the quality of care they received while residing in a Colorado nursing home and alleged that their rights had been violated (Brady, 2001). The plaintiffs also claimed that the government had failed to monitor nursing homes sufficiently to ensure that the residents receive adequate care (Brady, 2001). This case once again brought attention to the failures of nursing homes to deliver quality care and earn residents' satisfaction.

In 1980, while the class action litigation was proceeding, the Health Care Financing Administration (HCFA) revised the federal nursing home regulations regarding the process used to certify nursing homes for Medicare and Medicaid reimbursements (Brady, 2001). HCFA intended to shift the focus of the certification process from paper reviews that were designed to evaluate a LTC facility's capability to provide care, to a real-time assessment of the care actually delivered to the residents (Brady, 2001). However, during President Reagan's administration this effort was rescinded in favor of a new data-based approach to regulatory reform (Brady, 2001).

The legislative failures to pass new regulations led to HCFA and the Institute of Medicine (IOM) of the National Academy of Sciences (NAS) to conduct a study "that would serve as a basis for adjusting federal (and state) policies and regulations governing the certification of nursing homes so as to make those policies and regulations as appropriate and effective as possible" (Brady, 2001, p. 8).

The resulting IOM report, titled “Improving the Quality of Care in Nursing Homes,” published in 1986, identified serious problems in both the quality of care provided to nursing home residents as well as in the overall quality of life of the residents (Brady, 2001). The report stated that providing consistent high quality care in nursing homes to a varied group of frail, very old residents ... “required that the functional, medical, social, and psychological needs of the residents be individually determined and met by careful assessment and care planning” (Brady, 2001, p. 9; IOM Report, 1986, p. 10 - 11).

In 1987, in response to the IOM report, Congress passed sweeping legislation directed at monitoring and regulating the nursing home industry in the United States. The legislation, the Nursing Home Reform Act, incorporated in the Omnibus Budget Reconciliation Act of 1987 (OBRA), changed the ways individual states and the federal government monitor nursing homes and outlined the standards that function to protect the well-being of nursing home residents.

To achieve the goal of providing quality care that maximizes each resident’s functional abilities, LTC facilities are now required to meet over 130 conditions and standards (Brady, 2001, p. 12). These include, but are not limited to: (1) conducting an annual assessment of each resident; (2) creating an individualized care plan; (3) reducing the use of physical and chemical restraints; (4) ensuring staff receive additional training in the care of residents with cognitive impairment; (5) providing such basic services as nursing, dietary, physician, dental, pharmacy and rehabilitation services; and (6) enforcing and protecting resident’s rights. The tenets established and delineated by the Nursing Home Reform Act of 1987 echo the need to ensure quality care in nursing homes by hearing from all voices connected to the long-term care industry. However, little has been done since the legislation was enacted to capture and include the voices of families and the residents themselves.

The Nursing Home Reform Act was passed in 1987; however, enforcement of the regulations it put into place did not occur until 1995. Rather than working with the nursing home industry to establish and refine systems and procedures to ensure the best nursing home care possible, regulators shifted their emphasis (and directed their

resources) to ferreting out, punishing, and even criminalizing instances of non-compliance with the standards (Brady, 2001).

Notwithstanding the enactment and enforcement of the Nursing Home Reform Act, a disturbing picture of quality care failures has continued and, by some accounts, has become worse. For example, in 1998, the General Accounting Office (GAO) released a highly critical study of the California nursing home industry. The GAO sampled 62 cases of California nursing home residents who died in 1993 and found that 34 of the residents received unacceptable care, including unexplained and unmonitored weight loss as well as improperly treated pressure sores (Brady, 2001). The rising incidence of lawsuits based on allegations of inadequate care in cases of abuse, neglect, pressure sores and falls continue today (Brady, 2001; Johnson et al., 2004; Lachs & Pillemer, 1995; Marks, 1996; Stevenson, 2005). Tort reform in many of the United States may curtail some of the litigation; however failures to improve the conditions in the LTC industry remain.

As with many federal reform initiatives, regrettably the emphasis of LTC regulators has been directed towards formulating more and more regulations rather providing support for improving compliance and resident outcomes (Brady, 2001). Although the nursing home industry has been extensively researched and scrutinized since 1987, some critics claim that poor quality care and resident outcomes continue to mount because of over-regulation (Brady, 2001). Some believe that the consequent over-regulation with little or no improvement in the actual quality of services provided are symptoms of a broken system that spends more time worrying about regulations than finding ways to comply with them (Lachs & Pillemer, 1995; Marks, 1996; Stevenson, 2005).

Plainly, the complex regulatory framework created under the Nursing Home Reform Act of 1987 and related State laws have not remedied the root causes of deficient practices in LTC facilities. The idea that creating additional layers of regulations will lead to improved quality of care is ill-conceived and naïve (Brady, 2001). For legislation and regulation to truly foster quality in the more than 17,000 nursing homes in the United States today, there must be inclusion of the voices of residents and family members.



### Expectations of Quality Care: Links to Patient Satisfaction and Outcomes

While little has been done to research expectations of and measure satisfaction with care in the LTC industry, hospitals have a better track record of trying to listen to and please their customers. In 2000, Oermann and Templin conducted an exploratory study that looked at the attributes of quality health care from the perspectives of consumers. The study was based on a model developed by Kravitz (1996) that proposes a link between expectations of care and the patient's satisfaction in the context of a medical encounter (Kravitz, 1996). The model suggests, "patient's expectations of care are formed before the encounter and include expectations for care in general and for a specific visit" (Kravitz, 1996, p. 13). Kravitz explains that expectations are influenced by demographic characteristics, prior health experiences, and concerns related to the patient's specific health problems. The model proposes linkages between consumers' definitions of high-quality health care and their having access to health care, having competent and skilled providers, and receiving proper treatment. Patient satisfaction is also influenced by the patient's expectations and how the patient defines quality of care. Oermann and Templin's (2000) study added to the growing knowledge about care expectations and satisfaction by reporting outpatient consumers' perspectives that showed there were similar linkages and influencing interactions between them, as originally proposed by Kravitz.

The few studies have attempted to learn what residents of LTC facilities perceive as quality care and how they determine satisfaction with care. A review of these studies follows. Referring to a study conducted by Bliesmer and Earle in 1993, Chou et al. (2002) determined that "good staff care is important to residents and has a profound effect on them" (Chou et al., 2002, p. 197). Using a cross-sectional study design, Chou et al. (2002) examined the direction and magnitude of the effects of resident satisfaction with care, and determined relationships among measurable satisfaction variables across several types of LTC facilities (Chou et al., 2002). The team looked at the differences between LTC facilities and hostels, which in their study was defined as a personal care

home. The researchers used a short-form resident satisfaction questionnaire with a sound psychometric history in LTC studies and found that resident satisfaction was a multidimensional construct comprised of six factors: (1) room, (2) home, (3) social interaction, (4) meal service, (5) staff care, and (6) resident involvement. Chou et al. (2002) concluded that residents' perceptions of quality care were linked to satisfaction with staff and that staff played a central role in determining all other aspects of resident satisfaction.

Bliesmer and Earles (1993) used one of the three categories (structure, process, and outcomes) from Donabedian's (1988) work, in an outcomes approach to study what LTC residents viewed as indicators of quality care. The researchers aimed to discover if nursing home residents and nursing home staff had similar views about seventeen quality indicators. Data were collected during interviews with 15 residents and 15 nursing staff. A priori, the investigators hypothesized that "there should be congruence between resident and staff perceptions of the importance of indicators of quality in LTC settings" (Bliesmer & Earle, 1993, p. 34). However, minimal to moderate congruence of perceptions was found. Noteworthy, however, were the findings that prompt attention to needs and problem resolution were the two indicators of quality that were most important to the residents.

In 1996, approximately 17% of the 1.6 million residents of LTC facilities received assistance with two or less activities of daily living. Grando et al. (2002) became intrigued by these statistics and conducted a descriptive study asking why residents with light care needs enter and remain in LTC facilities (Grando et al., 2002). They concluded that older adults with light care needs who decide to enter and remain in a LTC facility were motivated by prior hospitalizations or health events, the perceived inability to manage activities of daily living, and a lack of knowledge of LTC alternatives (Grando et al., 2002). The findings of this study seem to echo those from the Kravitz (1996) study in that expectations are influenced by demographic characteristics, prior health experiences, and concerns related to the patient's specific health problems. Similar findings are reported in Chapters Four and Five of this study.

As concerns about quality dementia care rise with the numbers of individuals who seek and will seek care for this progressive neurodegenerative disorder, concerns about gathering expectations of dementia care also are on the increase. When looking at expectations of care from the perspectives of patients and residents, a major problem becomes apparent: Can an individual with dementia accurately describe and elucidate their expectations of care when the central issue of dementia is a lack of cognitive ability? Folstein et al. (1975) developed the Mini-Mental Status Examination (MMSE) as a screening tool to establish a diagnosis of dementia in cognitively impaired individuals. In two studies conducted by Iwasiw et al. (1996, 2003), that addressed residents' and family members' perspectives of care at two weeks and one year post-admission to a LTC facility, the researchers determined that a resident should achieve a score of 24 or more on the MMSE in order to be eligible to participate in the study (Iwasiw et al., 1996; Iwasiw et al., 2003). Questions about competency and abilities to understand questions posed in a research study prevail in the dementia community. Such questions and concerns are somewhat responsible for the paucity of research examining expectations of care from the perspective of individuals with a dementia diagnosis. However, the voices of their advocates have not been included in a robust way in studies of LTC expectations. More needs to be done to acquire this knowledge from spouses, children, guardians, and significant others so it can be used to improve services and outcomes for dementia patients.

#### Expectations of Quality Care: Residents, Patients, and Family Members

A qualitative study conducted by Train et al. (2005), investigated the positive and negative aspects of the experiences of LTC for residents with dementia, their relatives, and the staff (Train et al., 2005). Five main themes emerged from the analysis of narrative interviews with 21 residents, 17 relatives and 30 staff. These themes were: (1) privacy and choice, (2) relationships (abuse and vulnerability), (3) activities, (4) physical environment, and (5) expectations of a care environment by caregivers (Train et al., 2005). The study findings suggested that even though the caregiver (family member) was

no longer responsible for the day-to-day care of the patient after admission to a LTC facility, there still existed an increased level of psychological distress among some of the family members. In addition, individuals with dementia who were able to participate in the interviews provided insightful and meaningful data that contributed to understanding what was happening to them. A limitation of the study was that there were no MMSE scores collected and recorded to establish the level of dementia that affected each of the resident participants. Nevertheless, all participants talked about the need to “improve the lines of communication” (Train et al., 2005, p. 119). Again, the results of this study implied that expectations of the caregivers (family members) and the residents were not fully met when communication was in question. Recommendations of the researchers also included the need to develop programs that address the psychological distress reported by family members. This is an example of how broad a range there is among residents and family members when it comes to identifying conscious and unconscious expectations of LTC facilities and services.

Communication is also a thread reported in findings of satisfaction studies done across different populations of hospital patients and their family members. In 2005, Auerbach et al. looked at optimism, satisfaction with met needs, interpersonal perceptions of the health care team and the emotional distress in patients’ family members during critical care hospitalizations (Auerbach et al., 2005). The objective of the study was to compare satisfaction with met needs, signs and symptoms of acute distress disorder, interpersonal perceptions of health care staff and level of optimism among the patient, family and staff. The researchers found that while patients were unable to speak for themselves, family members became the major link between the patient and the critical care staff. The researchers concluded that the most significant aspect of care from the family member’s perspective was to receive “clear, understandable, and honest information about the patient’s medical condition” (Auerbach et al., 2005, p. 202). While they used a critical care family needs inventory, among other scales, to ascertain family members’ needs while dealing with a loved one in a critical care setting, a suggestion to conduct further research in expectations of care was implied in their conclusions when

they spoke about research engaging family members in the care of LTC patients with cancer and those dying of AIDS.

Riemenschneider and Raub's (2003) editorial about expectations of quality care in LTC settings stated that "today's patients and their families expect providers to demonstrate high levels of performance" and "the perception of the quality experience that people encounter in their daily lives will, in turn, define the level of quality they expect from long-term care providers" (p. 79). Efforts to work with families must not end following admission. Working together with LTC facility staff to understand patient care needs and align them with expectations and evaluations of outcomes remains critically important throughout a resident's lifetime. In sum, these authors underscore the need to know the expectations of quality care and to query family members who seek long term care for their loved ones with dementia.

#### Expectations of Care: Perspective of Family Caregivers

Levy-Storms and Miller-Martinez (2005) conducted a longitudinal research study that examined relationships between family caregivers' involvement in and their satisfaction with LTC care during the first year (Levy-Storms & Miller-Martinez, 2005). The investigators defined the primary family caregiver as "the family member who provides the most care" (Levy-Storms & Miller-Martinez, 2005, p. 163). The study sample included 145 family caregivers who completed a satisfaction survey near the time their care recipient was admitted to a LTC facility and again one year after admission. Having surveyed the family members at the time of the patient's admission and again one year later, the researchers found that caregivers were least satisfied with the physicians and were concerned about the lack of staff in general. Using multivariate statistical analysis (Pearson's correlations and factor analysis), they also found that the more involved caregivers were at the time of admission the less satisfied they were with institutional care at admission and at one year after admission (Levy-Storm & Miller-Martinez, 2005). The researchers concluded that caregivers who were more involved may be less satisfied because they see firsthand the problems associated with LTC and suffer

the loss of a meaningful caregiver role after admission (Levy-Storm & Miller-Martinez, 2005).

Braithwaite and McGown (1993) conducted a pre-test/post-test study designed to explore the capacity of caregivers labeled as “emotional” to learn about stroke in an applied setting (Braithwaite & McGown, 1993). The dependent variable was the knowledge gained about strokes and caring for individuals who have had a stroke. The intervention was a seminar about strokes and the care of persons with strokes conducted by the researchers. The researchers found that caregivers who were unable to control their emotions learned less, were perceived by the medical staff as being difficult, and were involved on a limited basis with interactions with doctors. While all participants received the same education program as an intervention, the researchers found that those with strong and uncontrollable emotions had lower scores on post-tests compared to individuals who were in better control of their emotions. Nevertheless, the researchers found that emotionally unstable family members were as capable of learning about stroke as those who were emotionally stable (Braithwaite & McGown, 1993). Based on the description of caregivers’ levels of emotionality from previous research conducted by Braithwaite (1987), the level of emotionality was described as low tolerance to stress, easily aroused emotions, and symptoms of anxiety and depression (Braithwaite, 1987). In the end, Braithwaite and McGown found that greater knowledge at post-test among caregivers with better mental health seemed to be a function of their pre-test knowledge rather than a greater capacity to learn (Braithwaite & McGown, 1993). They concluded that “successful intervention with stroke survivors may be increased by the adoption of a more dynamic conception of the caregiver’s needs” and “the challenge facing staff is to recognize the right time to provide information” (p. 201).

The results of these studies underscore the need for LTC facilities to recognize that the loved ones’ family members may be stressed and fragile when they reach the decision to place a family member in LTC, especially when they have been caregivers in the home for years. Further research needs to be conducted to explore caregivers’ expectations of quality care in an effort to facilitate greater caregiver health.

In 1989, a qualitative study conducted by Wilson, titled “Family Caregiving for a Relative with Alzheimer’s Dementia: Coping with Negative Choices”, explored and described the process of family care giving for elderly relatives with dementia as experienced by the caregivers (Wilson, 1989). The author used a grounded theory qualitative research approach. While this study was conducted in the late 1980s, the problems facing those who have to care for “loved ones” with dementia still prevail. For example, Wilson observed that there is a profound psychological impact upon those caring for someone whose disorder follows a downhill course with care needs progressively rising. She also reported that the risk of institutionalization is increased when the ability of the family member or caregiver goes over the brink of tolerability (Wilson, 1989). Wilson labeled the grounded theory that emerged from the narratives “Surviving on the Brink” (Wilson, 1989). The basic social processes that comprise this theory represent the experiences of the study groups’ trajectories of coping with caregiving challenges. Using the words of the study participants, the three stages of (1) taking it on, (2) going through it, and (3) turning it over were abstracted and labeled (Wilson, 1989). It was during the third stage that the caregivers made the decision to relinquish care to a third party, usually a LTC facility. This process is gradual, and considered a process of giving up control that requires caregivers to reverse previously held convictions that they could do it all themselves.

Considering the stress of caregiving and the emotional upheavals that institutionalization brings about, the time of admission to a LTC facility is the appropriate period during which expectations of institutional LTC should be elicited. While the stressors may also contribute to a mild memory loss related to overload, the caregiver is also more candid at this point in time and able to express demands clearly. Following up with education and negotiations as the time for admission nears is critically important to the development of an interactive definition of quality care and the determination of indicators that will assist in the evaluation of and satisfaction with care.

A longitudinal study by Wright et al., (1999) echoed Wilson’s findings. The investigators examined the emotional and physical health of spouse caregivers of persons

with Alzheimer's disease and stroke (Wright et al., 1999). Wright's team hypothesized that because of the progressive deterioration of patients with dementia, caregivers for these patients would experience more adverse health events than those caring for persons who had suffered a stroke. Their findings supported their hypothesis when data showed that caregivers of persons with dementia had higher levels of depression than stroke caregivers. They also found that dementia spouse caregivers experienced high levels of depression in the early phase of the dementia trajectory due to the uncertainty about the future and recommended that interventions with caregivers be directed toward the type and phase of the illness trajectory their loved ones are experiencing (Wright et al., 1999).

While there has been a dearth of reports about studies that specifically elicit expectations of quality dementia care, a wave of interest has swelled in the past two years. Most recently, a qualitative study published by Strang et al. (2006) titled "Family Caregivers and Transition to Long-Term Care" was designed to explore family members' experiences while awaiting nursing home placement of a loved one with dementia (Strang et al., 2006). The researchers decided to take a different path because, as described in a literature review, a panoply of family-related studies have been conducted taking issue with identifying predictors of placement, describing reasons to delay placement, looking at decision-making processes, and exploring transition problems after the resident was placed in the LTC facility (Ayers, 2000; Butcher et al., 2001; Chenoweth & Spencer, 1986; Clark & King, 2003; Gonzales-Osler, 1989; Lundh et al., 2000; Neilsen et al., 1996; Penrod & Dellasega, 1998; Rogers, 1997; Schwartz & Vogel, 1990; Shuttlesworth et al., 1982; Smallegan, 1985; Szabo & Strang, 1999; Strang et al., 2006; Wuest et al., 1994). From their perspectives, missing from the literature were descriptions of family members' experiences while awaiting placement of a loved one with dementia in a LTC facility. Once a decision was made for placement by the family member, the experiences of the caregivers in the study group clustered into the following themes: (1) crisis as an initiator, i.e. a sudden awareness of the loved one's mental and physical deterioration and a need for long-term care, (2) need for synchronicity, i.e. caregiver readiness for placement and the availability of a bed in a LTC facility, (3) control, i.e. a



search for help and guidance to maintain control, and (4) reciprocity, i.e. the [patient] cared for me; therefore, I need to care for [them] (Strang et al., 2006). While this study focused on some of the caregiver's experiences and expectations during the transition period, still missing from the literature are family members' expectations of the quality of care during that time.

Each of the aforementioned studies explored caregiver problems associated with caring for a person with long term or chronic health problems; however, they fall short of investigating the caregivers' expectations of quality care at the time of transition to a LTC facility. Such studies should be conducted however, as they have the potential to guide nursing home and family collaboration and promote greater satisfaction and resident outcomes. While the process of "turning it over" (Wilson, 1989) is known to be a traumatic event in the life of a caregiver, it is not known what their expectations of care are at transition and placement of their "loved one" in a LTC facility.

### Transition Experiences and Life Events

"Transition" is defined as a passage from one form, state, style, or place to another (American Heritage Dictionary, 2000). In 1999, Dai Williams presented a paper at the British Psychological Society's Occupational Psychology Conference in which he stated that most transitions are associated with some significant life event (Williams, 1999). He observed that changes to an individual's role or environment required restructuring of the individual's view of themselves and their world (Williams, 1999). When a family member or significant others' perception of reality is disrupted, perhaps by a need to relinquish care and place a loved one in a nursing home, then a life transition is more than likely initiated (Barba & Selder, 1995; Selder, 1989).

In 1976, when transition theories initially emerged, many were based on experiences individuals traversed involving bereavement, family crisis, and depression (Hopson & Adams, 1976; Kubler-Ross, 1972; Lewin as cited in Likert, 1947). According to Barba and Selder (1995), a life transition is initiated when a person's current reality is disrupted. A person's reality could change due to a crucial event, a determined decision,

or through a series of occurrences or events is recognized as causing a shift in their reality (Barba & Selder, 1995; Selder, 1989). For example, a husband and wife may have made special vows when they married that neither one of them would place the other in a “nursing home.” A crucial event may occur when the husband suffers a major stroke and the wife can no longer care for him in the home or a decision may be necessary when the husband is diagnosed with dementia and as he progresses through the dementia trajectory the wife must admit him to a nursing home. It is entirely possible that a combination of all the events that occur over time may contribute to the making of the final decision to place the “loved one” in a LTC facility. When confronted with this idea, such placement decisions are made at times of increased stress for all involved.

The theory of life transitions explains that as a process, a transition might help individuals “bridge” the reality that has recently been disrupted to a newly structured reality (Barba & Selder, 1995). Barba and Selder go on to say that the new emerging reality incorporates the event and decision so that the integrity of the person remains intact (Barba & Selder, 1995). The development of the new reality is based on the expectations of what the person believes that new reality to be when the old reality has been broken. The main thrust of the life transitions theory is how people restructure their reality and resolve uncertainty (Barba & Selder, 1995). It is the assumption of this investigator that discovering family members’ expectations are not only useful to the establishment of quality indicators and the evaluation of satisfaction with care, but the family members’ conversations about this topic may also be of help to them as they try to cope with this major life transitions.

When family members or significant others find they can no longer meet the needs of the dementia patient at home, a move to a nursing home may become the only solution. Duncan and Morgan (1994) conducted a qualitative research study which included 30 focus groups with 179 caregivers. The aim of the study was to describe stories of family caregivers’ interactions with staff in LTC settings where their loved ones with dementia resided. The caregivers were interviewed twice and five themes emerged after the transcripts of the data were analyzed. The five themes were: (1) events,

(2) the health care system, (3) the caregiver-care receiver relationship, (4) support, and (5) options and availability (Duncan & Morgan, 1994). It is interesting to note that when a male spouse caregiver was interviewed, the central focus of his concern was on the incontinence problems associated with dementia (Duncan & Morgan, 1994). When a female spouse caregiver was interviewed, the focus was on safety (Duncan & Morgan, 1994). Another finding was that the health care system had a negative influence and tended to delay the placement decision (Duncan & Morgan, 1994). One of the overall suggestions by these authors was to consider research for purposes of theory development. It was implied that transition theory development should be undertaken by more researchers studying populations of family members who care for loved ones with dementia.

Schumacher and Meleis (1994) began to describe transition as a concept of interest to researchers, theorists and clinicians. Their review of the literature from 1986 to 1992, Schumacher and Meleis found that “transition” was an important concept within nursing (Schumacher & Meleis, 1994). They described the universal properties of transition as process, direction, and change in fundamental life patterns. The conclusions of their review included transitions at the individual and family level, which consisted of changes in identities, roles, relationships, abilities, and patterns of behavior (Schumacher & Meleis, 1994). These findings have relevance when studying the changes in identities, roles, relationships, abilities, and patterns of behavior when a family member or significant other decides to admit a “loved one” in a nursing home. Schumacher and Meleis described both the conditions that may influence transition experience and the consequences of that experience and the indicators of a successful transition. The conditions that may influence the transition experience and consequences are meanings, expectations, level of knowledge and skill, environment, level of planning, and the emotional and physical well-being of the individual (Schumacher & Meleis, 1994). The indicators of a successful transition were described as subjective well-being, role mastery, and the well-being of the relationship (Schumacher & Meleis, 1994).

Wilson (1997), conducted a grounded theory qualitative study to determine the initial experiences of older adults who were admitted to a nursing home on a planned or unplanned basis (Wilson, 1997). This study looked at the nursing home resident who was able to participate and understand the instructions given. The study participants did not include dementia patients. In-depth, semi-structured interviews were conducted individually with 15 cognitively intact adults who were admitted to a nursing home (Wilson, 1997). The themes that emerged were that individuals went through three phases during the transition to the nursing home. The three phases were: (1) being overwhelmed, (2) adjustment, and (3) initial acceptance (Wilson, 1997). The results of this qualitative study have implications in studying family members' and significant others' phases of transition when making the decision to place a "loved one" in a LTC facility and adjustments people make after the fact.

In 2000, Meleis et al. conducted a conceptual analysis on the "transition framework" used in nursing to explain the changes that health and illness create. They note that transitions are both a result of and result in change in lives, health, relationships and environments (Meleis et al., 2000). They described the concept of "transition" as a middle-range theory. The theory of transition consists of types and patterns of transitions, properties of the transition experiences, the facilitating and inhibiting conditions, the process indicators, the outcome indicators and the health care interventions (Meleis et al., 2000). Their review of the literature included five studies that used a transition framework. While the results of their five study review have profound implications in the use of a transition framework, there are no studies cited that use the transition framework while studying the evolution of the decisions made when a family member or significant other decides to place a "loved one" in a LTC facility. However, since the publication of their conceptual review on "transition," several studies have emerged that have used transition as a central theme when describing the decision that a family member or significant other has to make when moving the "loved one" from a home environment to an institutional environment.

A grounded theory study that examined the way caregivers reach a decision for placing a loved one in a LTC facility was conducted by Stull et al. (1997). Caregivers were defined as persons who provided primary care for the elderly family member in the home. After interviewing 42 caregivers, one of the research conclusions supported the idea that making a decision to place a loved one in a nursing home began early in the caregiver's interaction with their loved one. Also, there evidence that the health problems of both the caregivers and the care receivers contributed to the nursing home placement decision (Stull et al., 1997). According to Stull et al. (1994), making the decision to place an elderly relative in a nursing home is often the most painful decision a family must make (Stull et al., 1997).

Other studies agree that placing an elderly relative suffering from dementia in an institution can be a very traumatic period of transition for the caregiver (Cohen et al., 1993; Colerick & George, 1986; Dellesega & Mastrian, 1995; Grando et al., 2002; Hagan, 2001; Johnson et al., 1994; Lieberman & Kramer, 1991). Gaugler et al. (2001), interviewed 185 dementia patient caregivers before and after the loved one was institutionalized. The researchers used multivariate regression analysis to identify relevant predictors of LTC search difficulties, professional help, and family help during the transition period from home to the nursing home. They concluded that the personal and social resources of the caregivers prior to placement were reliable search difficulties and perceived helpfulness (Gaugler et al., 2001). One of the limitations of this study was the lack of an association with a transition theory to support their assertions.

The stages of transition were first recognized by Kubler-Ross when she studied death and dying and described the stages of that process (Williams, 1999). Further work in the recognition of transition stages was done by Hopson and Adams (1976) when they described a model for career development. Additional research during the 1970s suggested that transitions could be activated by any major life event. The triggering life event can be "good" or "bad" and follows a natural progression of human responses to change throughout the transition cycle. These models may have usefulness in describing

the transition process which family members and significant others go through when making the decision to place a loved one in a LTC facility.

Another transition theorist, Nicholson (1990), has suggested that change due to a life event is not linear, but circular. He developed the Transition Cycle of Change model which demonstrates that changes or adjustments made in response to life events are cyclical. Nicholson's model was used in this study as the sensitizing orientation. As such, it guided the elicitation of life events as stories told by spouses and adult children who cared for a loved one with dementia and made decisions to relinquish care to a LTC facility.

Nicholson's model includes four stages of the transition cycle: (1) preparation, (2) encounter, (3) adjustment, and (4) stabilization (Nicholson, 1990). To lend credibility to his framework, he does not attempt to provide predetermined experiences. He merely suggests people encounter extremely different experiences in transition that can be interpolated and interpreted. In doing so, the transition cycle is guided by three principles: (1) recursion, (2) disjunction, and (3) interdependence. He explains these principles and the cyclic nature by stating: "Even the most stabilized conditions contain the possibility for future change, and, therefore embody varying states of readiness for the onset of a new cycle. For this reason, Stage I is also Stage V" (Nicholson, 1990, p. 87). Each stage has distinctive qualities; however, they are also interdependent. "What happens at one stage exerts a powerful influence over what happens at the next." (Nicholson, 1990, p. 88)

Nicholson (1990) further illustrates the three guiding principles as individuals circumnavigate the transition cycle by describing tasks and challenges encountered, pitfalls and problems that await them and suggested solutions from both internal and external support systems. Each of the five stages discussed by Nicholson are discussed as follows: In the preparation stage (Stage I), the individual achieves a state of readiness and having an awareness of one's feelings helps. No matter how well prepared an individual is, it is during the encounter stage (Stage II) that new and unexpected experiences occur. Coping abilities and trying to make sense of what is happening are helpful during this

stage. The adjustment stage (Stage III) shows the individual ready to make personal changes, develop new roles, and engage in relationship building. Finally, the stabilization stage (Stage IV) sees the individual establishing sustained trust, commitment and effectiveness that provide momentum for movement into the preparation stage (Stage I and V) of yet another transition cycle.

To describe the tasks and challenges as well as the pitfalls and problems of each stage, Nicholson (1990) offers some guidance and suggestions. He expresses that anticipation that stimulates the formulation of expectations and builds motives are an integral part of the preparation stage. He goes on to express that emotion and perception provide the foundation of the encounter stage. The adjustment stage is governed by assimilation and accommodation, and, finally, stabilization is dominated by actions and relationships that facilitate preparations for another transition cycle.

To illustrate the alternative, i.e. pitfalls and problems, Nicholson (1990) offers additional suggestions and descriptions. The preparation stage may be fraught with fearfulness, reluctance and unreadiness. The individual in the encounter stage may be in a state of shock, and experience rejection and regret. During the adjustment stage, the individual will feel like a misfit and degraded. Also, they will grieve the loss of control over their ability to adjust to the new situation. Finally, during the stabilization stage, failure and fatalism take on new meaning as dysfunctional relationships develop. Such pitfalls and negative experiences should be avoided with guidance and counseling.

At the time of a significant life event, such as the pronouncement of a diagnosis of dementia, the family operates by their own rules, makes necessary adjustments and functions accordingly. Once the diagnosis has been made, the caregiver assumes their role and enters the transition cycle of preparation, encounter, adjustment and stabilization. As the patient moves along the dementia trajectory, the family member becomes aware of the increasing burden of that care that is placed on the family. Then the realization that the family member is no longer capable of managing the care of their loved one and feelings of guilt pervade their consciousness. They eventually come to the conclusion they will have to consider placement in a LTC facility. This realization has

emerged through some thoughtful preparation and, again, a major life event occurred. Thus the family member begins the transition cycle once again with the initial expectations of quality care progressing full circle through the transition cycle to more developed expectations of quality care.

The family member may either accept and/or meet tasks or challenges that are associated with each stage of the transition cycle or succumbs to the pitfalls and problems each stage has to offer. If we can understand the family members' response to change through the cycle of transition from home to the nursing home, then health care professionals can participate in the process to help those family members accept the decision they made, and, therefore, avoid the negative consequences of their decision and help them with realistic expectations of quality care.

If we can understand the family members' or significant others' response to change through the cycle of transition from home to the nursing home, then health care professionals can participate in the process to help those family members or significant others accept the decision they made and, therefore, avoid the negative consequences of their decision and help them with realistic expectations of quality care.

### Summary

Many decades of study have contributed to an understanding of what it means to be a caregiver for a loved one and how relinquishing care to others is done under stress. What needs more study is how family caregivers formulate expectations of care that others will or do provide to loved ones after they are placed in LTC facilities because of cognitive and functional problems associated with having dementia.

Extant research that has examined caregiver-care provider relationships, consumers' satisfaction with health care and LTC and links between satisfaction with care and the expression of care expectations present challenging conclusions and recommendations that have given direction to this study. Nicholson's transition model has provides a context for this study in that changes and challenges that individuals move through during major life events can be viewed as cyclical and positive. It is with a



positive attitude that this study was conducted with the goals of making contributions to knowledge about expectations of dementia care that can be translated to the practice setting as means to improve dementia care, resident outcomes, and family satisfaction. Building on knowledge presented in this Chapter, it is the intent of this researcher to apply the findings to practice at the local and policy levels so that evidence-based practice standards as well as regulatory statutes can be developed.

The next Chapter, Chapter Three, describes the methods used in this study. Findings are presented in Chapter Four and discussed in Chapter Five.

## **CHAPTER THREE**

### **METHODOLOGY**

#### **Introduction**

The chapter begins with a brief review of the significance of the study, reviews the aims and research questions, and addresses in detail the research design and methods employed to answer the research questions.

The nursing home industry has remained under fire for failing to provide adequate care to residents (Frantz, 2004; Intaglialia, 2003; Johnson et al., 2004; Silverman & Rocke, 2002). Rising numbers of elderly with dementia who cannot be cared for at home promise to strain the system further. Questions about what constitutes quality care in long-term care (LTC) remain causes of concern for providers, regulators, payers, accreditation bodies, residents, and families. Consumers of LTC services want to know that when they place an elderly parent or spouse with dementia in a LTC facility, services provided will be of significant and expected quality (Ryan & Scullion, 2000; Schur & Whitlatch, 2003; Wilson et al., 1999).

Numerous studies have addressed issues of quality in LTC (Butcher et al., 2001; Clark et al., 2003; Colerick et al., 1986; Grant et al., 2002; Lieberman et al., 1991; Maas et al., 1991). Missing from the literature is the examination of family members' expectations of what constitutes quality dementia care. Their perspectives can make important contributions to culture change in LTC (Iwasiw, 1996; Maas et al., 2004) and must become part of the dementia care paradigm.

The findings of this study will begin to fill the gap in knowledge about family expectations of quality dementia care by illuminating the basic social processes in "Coming to Terms" that reveal caregivers' transitions and experiences that influence the formulation of expectations. Findings are potential contributing building blocks for educational and support programs that advanced practice nurses can develop to facilitate

families making healthy adjustments to having loved ones with dementia in LTC facilities. Furthermore, findings will contribute to the development of more specific and effective consumer-driven industry regulations and indicators of quality care in LTC.

In review, the aims of this study were to: (1) elicit subjective perspectives of family members about what constitutes quality LTC for loved ones with dementia, and (2) develop a grounded theory of shared meanings about quality dementia care that reflects the expectations of family members in various stages of giving care and relinquishing care for a loved one with dementia. To achieve the aims of this study, grounded theory methodology (GTM) was employed to answer the research question: How do family members describe their quality of care expectations when a relative with dementia is admitted to a LTC setting? The remainder of this Chapter presents detailed descriptions of this study's methods, procedures, trustworthiness, human subject protection, and references to codebooks that validate data analysis and are found in the appendices.

## Methodology

### *Design*

This study employed grounded theory methodology (GTM) (Glaser & Strauss, 1967; Glaser, 1992) to achieve the aims and answer the research question. The relevance of GTM to the specific aims and research questions posed in this study was based on: (1) the assumption that family members' own experiences as caregivers for a loved one with dementia laid the groundwork for the development of their own expectations of quality care provided by others, and (2) the paucity of qualitative research done to elicit and interpret these expectations. Glaser & Strauss (1967) maintain that GTM serves a researcher well when few former studies were conducted about the phenomena of interest and when aims focus on theory development. It was this researcher's intent to not only gain an understanding of family members' expectations as queried in the research question, but to use the themes and basic social processes embedded in the grounded

theory as voices of family members that must be part of policy refinement and LTC culture change.

GTM emerged in the late 1960s from the seminal work of two sociologists, Barney Glaser and Anselm Strauss (Glaser & Strauss, 1967). This qualitative research method has its roots in sociology and rests on the philosophical and epistemological principles of symbolic interactionism. At the heart of symbolic interactionism is the premise that people develop meanings for the events in their lives and formulate guidelines for acting and behaving by interacting with other people and phenomena (Glaser & Strauss, 1967). As thoughts and actions change over time as a result of interactions with other people and phenomena, new meanings and guidelines for daily living emerge (Dey, 1999; Fernandez, 2004).

Theory grounded in the narrative data is the outcome of GTM and is comprised of and represents basic social processes found in the narratives of study participants as they share their stories of interactions and reveal their behaviors (Glaser & Strauss, 1967). Grounded theories are characteristically emic in nature in that they describe subjective human experiences as revealed by members of a study group rather than the views and hypotheses of the researcher or numbers reported as performance data when research measures are used to standardize and reduce humans to numerical representations (Glaser & Strauss, 1967).

The natural setting for this GTM was the meeting place chosen by each participant. The place where the caregiver and patient interacted was not considered the natural setting for this study because it was important for each participant to feel safe and free to discuss any aspect of the processes they journeyed through, including how they arrived at determining quality of care expectations. The locations for the interviews used to collect narrative data were private and were the preferences of the participants.

The data in this study were the narratives or stories revealed by the participants during semi-structured interviews with the investigator. The researcher was the primary data collection tool. He conducted each interview to purposefully elicit family members' expectations of care, their reflections upon the processes involved in making the decision

to admit their loved ones to LTC, how they went about formulating and defining quality standards for dementia care, and how their expectations remained fixed or changed over time.

The narratives or stories told by members of the study group were recorded, transcribed, and analyzed for themes that impart special meanings about the topic of interest. All participants were asked the same questions during individualized interview sessions (See Appendix C). The rules and assumptions of GTM that include the act of bracketing and measures of truth value assured that the findings represented the family members' expectations and not those of health care professionals, government bodies, or others outside the family. Grounded theory also uses a constant comparative approach as the grounded theory emerges from the data. Constant comparison will be addressed in detail in the data analysis section of this chapter.

Establishing an audit trail, using bracketing, and conducting member checks were among the strategies this researcher used to ensure that the reported findings represented the perspectives of the study participants. Truth value, trustworthiness, and scientific rigor are addressed in detail later in this Chapter.

### *Sensitizing Orientation for the Study*

In qualitative studies, sensitizing orientations may be models or theories that serve to inform the researcher and the study in several ways. They may contextualize and delimit the phenomena of interest and guide the development of sampling procedures to guide the development of a theoretical sample. Theory testing was not the objective of this research study. Rather, the sensitizing orientation for this study justified this investigator's sampling model and guided the selection of eligibility and inclusion criteria for potential participants. Details of this study's subject recruitment and enrollment plan can be found in the sampling section that follows.

Based on a review of literature, relinquishing the care of a loved one with dementia and placing him or her in a LTC facility is viewed as a major transitional event in the lives of both the individual being placed and his or her family members. For

purposes of this study, the significance of this *transition* is found in the stories of family members' experiences with making the decision to place the loved one, preparing to admit him or her to the facility, determining what one expects from staff at the facility, and coming to terms with their own new roles as family composition, dynamics, and caregiver responsibilities change.

The sensitizing orientation for this grounded theory study was Nicholson's Transition Cycle of Change (1990). It served to guide this researcher in building the context within which perspectives and stories of participants were elicited, data were analyzed, and findings were interpreted. Nicholson's perspective suggests that individuals experience four challenges as they circumnavigate life-altering transitions. The challenges are: (1) preparation, (2) encounter, (3) adjustment, and (4) stabilization. He further purports that "what happens at one stage exerts a powerful influence over what happens at the next" (Nicholson, 1990, p. 88). Therefore, it was the goal of this investigator to purposefully sample family members in the preparation and encounter phases of the cycle, during which time expectations of care were being formulated. Details of Nicholson's model were presented in Chapter One, Figure 1.1.

### *Sampling Model and Procedures*

Following Institutional Review Board (IRB) approval, the sample for this GTM was purposefully recruited as a theoretical sample, deliberately assembled to represent the broadest range of perspectives on the topics related to the aims of this study (Glaser & Strauss, 1967). GTM requires that a study sample be recruited from a population of persons who interact with the phenomena of interest and that emerging meanings and theoretical structures drive further sampling. Participants for this study were recruited throughout the duration of the study until data saturation and redundancy were reached and the demographic descriptions of participants affirmed that the goal of maximum variation was achieved (Lincoln & Guba, 1985).

Recruitment flyers (Appendix E) were posted at the cooperating LTC facilities with approval of administrators. Sample recruitment was facilitated by the administrators

and admissions coordinators at the three LTC facilities located in a major city in the southwest United States. The facility administrator's primary actions were to circulate information about the study and inform interested family members about how to contact the researcher to ask questions and get more information. The collaborating facilities represented private, government-sponsored, and public sectors of LTC service providers. Varying the types of LTC facilities from which the sample was drawn facilitated access to a multi-ethnic, multi-cultural, and multi-socioeconomic population.

There were positive and negative aspects to having administrators and admissions coordinators at the three LTC facilities assist with sample recruitment. Their own biases were found to operate to screen out potential participants, whom they felt were angry or would otherwise have only unfavorable things to say about a facility. To control for these biases, recruitment strategies included publication of announcements about the study in each facility's family council newsletter, in letters describing the study to responsible parties, and in each facility's reception area. Information about how to contact the investigator directly for more information was provided in each of the above study announcements. Word of mouth spread throughout the LTC community, locally, as participants who completed their participation recommended the study be considered by friends and others they knew in similar situation. Equal efforts were carried out to recruit and enroll men, women, and individuals of minority status. Children under the age of 18 and prisoners were not eligible to participate in the study.

Individuals in the community who believed they met eligibility criteria called the researcher about the study to learn more and to find out how to participate. Three individuals, after learning more about the study from the researcher, decided not to participate. Another potential participant was ruled ineligible for enrollment in the study because he was a legal guardian and not a family member.

Thirteen participants enrolled in and completed the study. Inclusion criteria required that study participants be caregiving spouses or adult children of loved ones with dementia who were recently or about to be admitted to a LTC facility. Guided by Nicholson's (1990) challenges of preparation and encounter, participants' stories about

this transitional period in their lives were collected by interviews between two weeks prior to their loved ones admission to LTC and three months post-admission. Eligible participants were required to speak and understand English, be 18 years of age or older, and be available to meet with the investigator for interviews at a place of their own choosing. Every effort was made to recruit and enroll male and female participants of varying educational, ethnic, and socioeconomic backgrounds. Themes that emerged from the on-going analysis of interview data guided the continuing recruitment of the theoretical study sample until redundancy was achieved, no new themes emerged, and the basic social process was apparent (Dey, 1999; Glaser & Strauss, 1967; Iwasiw et al., 1996; Lincoln & Guba, 1985; Sandelowski, 1986; Strauss & Corbin, 1990).

A complete and detailed description of the sample of participants is presented in Chapter Four. The following section describes measures taken to protect human subjects.

#### *Protection of Human Subjects*

Both the university IRB and that of the government-sponsored institution approved the study. Written informed consent (Appendix A) was required for participation. Only eligible persons who volunteered to participate and who signed the informed consent were enrolled in the study. The consent form contained all essential information and required and standard clauses written in understandable language. Those who could not read the document had it read to them.

All potential participants were given the opportunity to ask questions and have their questions answered to their satisfaction by the investigator. Those who agreed to participate in the study signed two copies of the informed consent form and were given a copy to keep. The other copy of the informed consent remained with the researcher. Only after they had signed the informed consent did the investigator ask potential participants to make an appointment to be interviewed at a convenient time and location.

After eligibility was confirmed and the consent form was signed, an appointment was made for the first interview. Data collection took place during interviews conducted in a private location and at the convenience of the consenting participants.



Interviews were guided by the IRB-approved semi-structured interview guide (Appendix C). Bio-demographic data were also collected using an IRB-approved form created for the study (Appendix B). All study materials were coded with a number to protect the identities of the participants. There was minimal risk for the loss of confidentiality and this was communicated in the informed consent. Interviews were designed to last no more than 90 minutes at each session. No more than three sessions with any participant were anticipated. The number of times each participant was asked to meet with the investigator depended upon how long it took to complete the interview guide. All participants were asked the same questions during individualized interview sessions. All interviews were conducted during one session except for two study participants. Those study participants required two sessions. Each of these individuals stated they needed to go to an appointment and asked to schedule another interview session. This was done for each of them.

Information in the consent forms told participants that they could stop the interviews or withdraw from the study at any time without harm or penalty. As an advanced practice nurse with skills to recognize discomfort in a participant, the researcher kept the length of the interviews within the fatigue tolerance time of each individual. When there were signs that the intensity of the discussion was a potential source of anxiety, the interview was stopped or redirected to a less sensitive topic. Any participant who requested a referral to a counselor, organization, or facility for information or support was given one. No participant during the study requested any referrals.

Audiotaped interviews, transcripts, and demographic data sheets were coded with the numbers the researcher assigned to the participants. Signed consent documents were kept in a locked file in the investigator's office. Coded tapes, interviews, transcripts, and demographic data sheets also were locked in a file in the investigator's office but separate from any identifying materials.

### *Data Collection*

Grounded theory, an inductively developed outcome of GTM, reveals the basic social process found in the analysis and interpretation of narratives shared by members of the study group with the researcher. Open-ended, semi-structured interviews (Appendix C) were the primary data collection tools that were used to elicit family members' expectations of quality dementia care as they admitted their parent or spouse to a LTC facility. The narratives or stories told by members of the study group were recorded, transcribed, and analyzed for themes and the emergence of a basic social process. All participants were asked the same questions during interview sessions. The rules and assumptions of GTM ensure that the findings represent the family members' expectations and not the expectations of health care professionals, government bodies, and others outside the family.

Bio-demographic data collected in this study fulfilled the purposes of describing the sample, ensuring maximum variation among participants, and illustrating the characteristics of the loved ones that the sample cared for (Appendix B). Data collected about participants included: (1) age, (2) gender, (3) ethnicity, (4) relationship to the loved one being cared for, (5) marriage number (if spouse), (6) number of years caring for the patient at home or other location, (7) occupation, (8) number of children in the family, (9) type of social support used or preferred, and (10) previous experiences or acquaintances with another's admission to a LTC facility (self, relative, or friend). Bio-demographic data collected about the loved one being cared for (parent or spouse) were: (1) age, (2) gender, (3) number of years diagnosed with dementia, and (4) years of school completed. No medical records were accessed for this study.

Following informed consent, each participant identified the times and places when and where he or she wished to be interviewed by the investigator. Private interview rooms were available at each facility or the investigator conducted interviews in the participant's homes if they chose. The open-ended, semi-structured interview guide and the bio-demographic sheets designed for this study were used during the face-to-face interviews to ensure that each participant was given the same opportunities as the others

to respond to the same questions asked by the investigator. The numbers of interview sessions each participant was asked to engage in depended upon how much time was required to complete the interview questions. At least one but no more than two interview sessions were conducted with any participant. No interview session lasted longer than 90 minutes. The number of meetings needed was dependent upon the amount of time each participant needed to give full and rich answers to the interview questions and the time the investigator needed to clarify anything in the narratives.

The interview guide questions were open-ended questions with probes that explored topics that included transition to the LTC decision, expectations of medical care, expectations of nursing care, expectations of rehabilitation maintenance and recreational expectations (Appendix B). The probes served to remind the researcher to search the participants' answers for richness. Since sample size was determined by data saturation and redundancy (Lincoln & Guba, 1985; Sandelowski, 1986), the recruitment of new participants ceased when no new themes emerged from the data and thematic meanings became repetitious.

As described in the section on Protection of Human Subjects, all study materials were coded with a number to protect the identity of each participant. Names and other identifying information do not appear on any tapes, transcripts, or findings. Study materials are locked in a file inside the investigator's office. Consent forms and the researcher's log are locked up separately from the materials that contain study data. All interviews were audio-taped for transcription and analysis. Transcriptions were performed by the investigator as a means to stay close to the data and make decisions related to analysis and theoretical sampling.

### *Data Analysis Procedures*

Data was analyzed using iterative interpretation strategies and coding processes outlined by Glaser and Strauss (1967). Bracketing, establishing an audit trail and performing member checks were used to control for researcher bias, examine validity,

and ensure that the findings are true representations of the participants' stories. These details are presented in the section on rigor.

Data analysis was conducted simultaneously with data collection. Data analysis began with a line-by-line reading of each transcript so the researcher had the chance to sense the wholeness of the story prior to searching for themes and reducing the data. In GTM, it is during data analysis that hypotheses and themes are generated amongst the narratives to explain patterns of behavior contained in the participants' descriptions. In addition to thematic analysis, a method called constant comparison was used to identify categories of meaning and eventually the basic social process that were recognized as the grounded theory.

Procedures carried out during data analysis included: (1) reducing the raw data, (2) identifying themes in the data, (3) comparing themes across the data sets, (4) interpreting the meanings of the themes and organizing them into categories by commonly shared meanings, and (5) determining the reliability or consistency of judgment used during coding through the application of triangulation principles. To clarify the movements of the researcher through the data, first, open coding reduced the raw data and identified themes within the narratives. Coding then proceeded successively through three levels. At Level I, codes were written as the study participant stated them. Level II coding directed the collapsing of Level I codes into broader thematic categories. Level III codes, developed by collapsing and abstracting meanings found among the data in the Level II codes, generated the constructs of the theory. Throughout data analysis, the researcher kept detailed methodological notes and memos that recorded thoughts about the nature of the phenomenon, the emergence of new codes and categories, relationships between categories, and comparisons of emergent processes with those found in the literature (Smith & Biley, 1997). The next several paragraphs describe in detail for the reader how the narrative data in this study were analyzed and interpreted.

All taped interviews in this study were transcribed by the researcher, verbatim, using word processing software and a computer. After transcriptions were complete, the researcher listened to each tape and compared the tape to the written transcript to make

sure the tape was transcribed correctly. Then, in the order the interviews were conducted, transcripts were analyzed line-by-line for instances of data that study participants used to describe their experiences, behaviors, and expectations. These selected instances of data were coded according to the meanings they imparted in the context of each participant's story. Additional instances with similar meanings, found across the stories of the study group, were coded similarly and clustered by the Level I codes into units of meaning. These strategies were repeated over and over again with each subsequent interview until no new Level I codes emerged from the narratives.

At the time that saturation of Level I coding was apparent, a total of 44 meaning units (clusters) had emerged from the data. The label for each meaning unit was selected according to the dominant instances of data found in each of the 44 units or clusters. To establish the auditable trail, all 44 units of meaning were displayed in Code Book I, accompanied by the instances of data that described the common meanings that brought them together in the unit or cluster (Appendix F). The saturation of Level I codes occurred when interviews with the seventh participant were completed and analyzed. The analysis of the remaining six participant's narratives demonstrated instances that was consistent with and repetitive of those already supporting the emergence and labeling of the extant units or clusters. No new emergent thematic material was evidence that meanings identified and classified in Code Book I had reached saturation and that the data were ready for the next level of inductive analysis.

After reviewing and interpreting all the instances of data in Code Book I, the researcher applied constant comparison strategies among and between the 44 units of meaning. Data were recoded and collapsed into four thematic areas during these Level II coding operations. Level II coding operations involved the investigator's intensive search for broader, more abstract units of meaning that would serve to more parsimoniously represent descriptions of phenomena that were revealed by the participants. That is, across and between all of the 44 Level I meaning units, the investigator used inductive logic to review and discover broader conceptual classifications of shared meanings that captured and represented the merging of smaller and similar meaning units into more

abstract understandable themes. Four thematic clusters of meanings emerged from this exercise during which smaller units with similar meanings collapsed onto each other, resulting in richer and thicker descriptions of caregivers' experiences, behaviors, and expectations.

The following four thematic clusters of phenomena emerged during Level II coding were: (1) the resident's life prior to the decision for nursing home placement, (2) the family member's interaction with the resident prior to the decision for nursing home placement, (3) the decision to place resident in long-term care, and (4) expectations of care in long-term care. Once preliminary Level Two coding was completed, each of the four themes that comprised Code Book II (A) (Appendix G) was reviewed and analyzed. Again, constant comparison strategies were applied resulting in the further collapsing of meaning units as displayed in Code Book II (B) (Appendix H).

Throughout the coding and analysis operations, the researcher was actively engaged in triangulation. Triangulation means that the theoretical constructs that emerge from data are a result of the researcher's synthesis of what was occurring between the data, the literature, and the central emergent themes (Cutcliffe, 2000; Glaser & Strauss, 1967; Smith & Biley, 1997; Strauss & Corbin, 1990). Triangulation data were comprised of field notes that were recorded during the times the researcher was recruiting and collecting data. The notes describe people, situations, and dynamics related to the contexts and settings where interviews were conducted. Methodological notes that document the researcher's thoughts about and responses to data analysis procedures and outcomes are part of this study. Field and methodological notes were used in this study to verify emergent meanings and their classifications. Collectively, the notes record decisions made during constant comparison strategies where the researcher was collapsing data across and between meaning units to arrive at more abstract conceptual organizations of meanings and finally, the core category in which the basic social process operates (Smith & Biley, 1997).

When constant comparative data analysis strategies culminated in the identification of a core category, it marked the end of open coding and marked the

beginning of selective coding. Selective coding only applies to the data that were relevant to the core variable. It aimed to systematically relate the core variables to other categories, validating those relationships and filling in categories of data that needed further refinement and development.

In this study, “Coming to Term” emerged as the basic social process or explanatory framework that revealed, defined, and explained the participants’ experiences, behaviors and expectations in the context of delivering care to loved ones with dementia. When all the concepts and processes in an explanatory framework are linked together, the result is said to be ‘grounded theory’ because it emerges from the data provided by the participants (Chenitz & Swanson, 1986; Eaves, 2001; Glaser, 1978; Morse, 2001). Details about the findings of this study are presented in Chapter Four and discussed in Chapter Five. Throughout the entire data analysis process, the researcher used memos and notes to document his ideas about the data, codebooks, and themes.

The following section addresses the evaluation of this study’s scientific rigor and truth value.

### *Rigor*

The ‘gold standard’ for evaluating the rigor and truth value of qualitative research studies is credited to Lincoln and Guba (1985). They established four criteria for evaluating trustworthiness. They are: (1) credibility, (2) dependability, (3) confirmability, and (4) transferability (Lincoln & Guba, 1985; Graneheim & Lundman, 2003; Sandalowski, 1993; Wilson & Hutchinson, 1996). It should be noted that these criteria are not just for the data alone, but represent the evaluation of the interpretations and conclusions.

In this grounded theory study, trustworthiness was established by checking that the procedures and interpretations of the data were credible, dependable, confirmable, and transferable. Rigor or trustworthiness was measured against these four criteria as described in the following section.

Credibility in qualitative research is concerned with the confidence in the truth of the data and the interpretation of those data. Credibility in qualitative research is associated with validity in quantitative research (Lincoln & Guba, 1985). Lincoln and Guba have described several techniques associated with establishing of credibility. Triangulation is one of the most popularly used techniques when demonstrating the credibility of a qualitative research study. Triangulation is defined as the use of multiple referents to draw conclusions about what constitutes the truth. The purpose of triangulation is to overcome intrinsic bias that comes from single-method, single-observer, and single-theory studies (Denzin & Lincoln, 1998). It has also been suggested that triangulation helps capture a more complete and contextualized picture of the studied phenomenon.

For the purposes of this grounded theory study, data source triangulation and investigator triangulation were used to establish credibility. Data source triangulation was accomplished by selecting a study sample with diverse backgrounds and varied demographics. All were asked the same questions during interviews and all cared at home for their loved ones with dementia prior to decisions to admit them to LTC. Investigator triangulation was employed in this study specifically to address data validity and the validity of methods and decisions used during data analysis and interpretation (Denzin & Lincoln, 1998; Guion, 2002). Faculty members of this dissertation supervisory committee participated. Using the two triangulation procedures discussed above, the researcher concluded that the procedures and findings of this study converge on the truth. No irregularities were discovered.

Another technique associated with credibility is external checks that include peer debriefing and member checks. Peer debriefing involved meeting with committee members and other qualitative methods experts to review and validate data analysis procedures and conclusions performed during the study. Member checks for this study involved soliciting study participants' reactions to preliminary findings and interpretations. Three participants volunteered to review the decisions the researcher made regarding interpretations of the stories and the labeling of shared meanings. All



verified the researcher's conclusions and accurately portrayed what they had revealed during the interviews. Lincoln and Guba (1985) believe that member checks are one of the most important techniques used to establish credibility in qualitative research.

Dependability is the next criterion that contributes to evaluating trustworthiness in qualitative research. While credibility in qualitative research is associated with validity in quantitative research, dependability is associated with reliability (Lincoln & Guba, 1985). There can be no credibility in the absence of dependability. The suggested technique associated with establishing dependability for this qualitative study was that of inquiry audits. The inquiry audit involved the use of an external reviewer to scrutinize the data, its coding, and all relevant supporting documents. Throughout this study, the dissertation supervisory committee chairperson conducted audits of demographic data, transcripts, Code Books, and supporting descriptions of the emergent core category and basic social process.

The third criterion of trustworthiness is confirmability. Confirmability is associated with the objectivity and neutrality of the data. In others words, confirmability is the potential for congruence between two or more independent people about the study's accuracy, relevance, or meaning (Lincoln & Guba, 1985). Bracketing and journaling are two methods that can enhance confirmability. Nurses and researchers in the clinical setting evaluated the confirmability of this study when the investigator brought insights about the study and its data to them. The expert clinicians, researchers, and educators on this dissertation committee will further evaluate it.

To enhance confirmability and dependability, the researcher used inquiry audits. In an inquiry audit, the researcher developed and recorded an audit trail. An audit trail is a systematic collection of documentation that allows an independent auditor to come to conclusions about the data. After all the research documents were assembled, an auditor proceeded to review all the documents and audited the trustworthiness of the data and the meanings attached to them. This researcher established an audit trail by keeping appropriate records. The necessary documents that produced the audit trail were: raw data (field notes, interviews), data reduction and analysis products (theoretical notes), process

notes (member check notes), material related to intentions and dispositions (personal notes on intentions), instrument development information (pilot topic guides), and data reconstruction products (draft of final reports).

The researcher also enhanced the auditability (the degree to which someone can follow the researchers' methods, decisions, and conclusions) by recording a decision trail. A decision trail was included for all coding operations and decisions related to categorizing analyzed data and making inferences. The Code Books found in the appendices of this dissertation provide volumes of decision trails.

Lincoln and Guba (1985) also recommend that transferability be evaluated as a means to establish trustworthiness in qualitative research. Transferability occurs when the findings from the data can be 'transferred' to other settings or groups and is similar to the concept of generalizability (Lincoln & Guba, 1985). Details that are provided throughout the research report will allow other researchers to replicate the study in their own settings and apply the results to settings that mirror the participants and procedures described in this dissertation. Lincoln and Guba state that the researcher must provide a thick description of the research setting as well as the transactions and processes observed during the research project (Lincoln & Guba, 1985). This dissertation report provides detailed descriptions of each

### Summary

GTM methods and procedures were used in this study to collect and analyze participants' stories of their experiences, behaviors, and expectations related to being in-home caregivers for loved ones with dementia. Following IRB approval, participants were recruited using flyers and postings in LTC facilities and throughout the community. Consenting volunteer participants comprised the 13-member sample that was demographically diverse. Interviews were conducted in private locations, were audiotaped and transcribed, and analyzed according to Glaser and Strauss' (1967) procedures for open, selective, and theoretical coding. Code Books, field and methodological notes provide the auditable trail for this study. The trustworthiness of the

study and its findings were evaluated using criteria established by Lincoln and Guba (1985). Findings and the description of the sample are provided in Chapter Four.

## **CHAPTER FOUR**

### **FINDINGS**

#### **Introduction**

The findings of this grounded theory study are presented in this chapter. The findings are in two forms. The first is an emergent theory titled, “Coming to Terms”: A Grounded Theory of Dementia Caregivers’ Journeys and Expectations of Care, that is displayed and described as a model comprised of five stages and nine behavioral phenomena that are grounded in the narratives of a group of family members experiencing the placement of a love one in a long-term care (LTC) facility. The second type of finding is a set of six categories of dementia care expectations that were inducted during the analysis of the study group’s narratives. These specific care expectations that family members revealed in their narratives emerged within and throughout the context of the social process, “Coming to Terms” (See Figure 4.1, p. 64). Tables 4.1, 4.2, and 4.3, presented later in this introductory section, provide a summary of all study findings. Detailed findings are presented following the Tables and the description of the sample.

The analysis of this study’s narrative data followed the procedures associated with grounded theory methodology (GTM), as described in Chapter 3. Codebooks I, II (a), II (b), also discussed in Chapter Three, are displayed in Appendices F, G, and H to illustrate the inductive coding operations used and cognitive decisions made by the investigator as data were deconstructed, unitized, conceptualized, and reconstructed into meaningful wholes (Glaser & Strauss, 1967).

The major findings of this study are accompanied by instances of data taken directly from the participants’ narratives. Instances of data are the actual words the study participants used during interview sessions with the investigator. They serve to support the inducted meanings and interpretations the investigator presents and illuminate the rich and thick descriptions participants provided about their subjective perspectives and

experiences (Glaser & Strauss, 1967). Equally as important, the selected instances displayed throughout this Chapter also are evidence that the findings represent the emic perspectives of the participants rather than the etic views and biases of the researcher (Pike, 1954; Lett, 2008).

The findings of this study, organized in the two forms discussed above, address the achievement of the aims of this study and answer the study’s research question. In review, the aims of the study were: (1) to elicit subjective perspectives of quality dementia care and transition experiences among a sample of family members whose spouses or parents are placed in or will be admitted to a LTC facility, and (2) to develop a grounded theory of shared meanings about quality dementia care to guide potential new quality-of-care indicators that reflect the views and standards of families and residents. Both aims were achieved when the “Coming to Terms” model emerged as grounded theory and the real expectations of dementia care were inducted from the shared meanings found in the narratives. The research question answered by both forms of findings was:

How do family members describe their quality of care expectations when a relative with dementia is admitted to a long-term care facility?

In the following three Tables (4.1, 4.2, 4.3), an overview of this study’s findings is presented. Following the Tables and a description of the study sample, a detailed presentation of the findings is presented.

Table 4.1: Summary Table of Family Member’s Stages (Transitions): “Coming to Terms”

Stages in Caregiver Transitions: “Coming To Terms”	
Stage 1	Family member transitions to caregiver role
Stage 2	Family member takes on caregiver role
Stage 3	Family member relinquishes caregiver role
Stage 4	Family member selects and evaluates the LTC facility
Stage 5	Family member accepts LTC resident status

Table 4.2: Summary Table of Behavioral Phenomena Experienced by Family Members:

“Coming to Terms”

Behavioral Phenomena That Inform Expectations	
Seeing Losses	Family member observes the loved one is changing
Filling Gaps	Family member performs as caregiver
Recognizing Limits	Family member recognizes his or her own limitations
Acknowledging Need for LTC	Family member acknowledges need to relinquish care
Responding to Relinquishment	Family member expresses emotions about decision for LTC
Making Selection	Family member carefully chooses preferred residence
Evaluating Care	Family member critically appraises facility effectiveness
Accepting LTC Status	Family member revises care expectations
Justifying Placement	Family member accepts ability of LTC facility to provide care

Table 4.3: Dementia Care Expectations of Family Members: Six Categories

Six Categories of Dementia Care Expectations
1. Patient Care, i.e. nutrition, hygiene, toileting, medications, and activities
2. Pleasant Surroundings, i.e. resident’s room and facility common areas
3. Competent Staff, i.e. dementia care and care of individuals in LTC
4. Caring Staff, i.e. treated with dignity and respect and free from neglect and abuse
5. Communication, i.e. what is communicated and when communication should occur
6. Institutional Responsiveness, i.e. staff response to questions and concerns

Immediately following a description of the sample, details about the findings of this study are presented.

### Description of the Sample of Participants

The sample in this study was made up of 13 family members of individuals with a diagnosis of dementia who were about to be or were already admitted to LTC facilities in a large metropolitan area in the southwest United States. Each participant met the eligibility criteria and willingly gave written informed consent. Study participants were either spouses, adult children, or other relatives of individuals with dementia. Of the 13 participants, one (8%) was recruited from the population of family members known to the admissions staff of a faith-based long-term care facility, five (38%) were respectively recruited from a government-sponsored LTC facility, five (38%) were recruited through word-of-mouth by those who knew about and considered participating in the study, and two additional participants (16%) were recruited through the use of flyers posted in a community-based LTC facility. The recruitment strategies and enrollment goals used in this study represent the investigator's aim to capture the broadest range of experiences with and perspectives on the phenomena of interest. Lincoln and Guba (1985) describe these strategies as providing a maximum variation sample that is important in qualitative research when randomization is not possible and representative samples cannot be statistically guaranteed.

All participants identified themselves as primary decision-makers for their family member with dementia. Of the thirteen study participants, five (38%) were spouses of the person with dementia, seven (54%) were adult children, and one (8%) was a cousin. Of the spouses, four (80%) were wives and one (20%) was a husband. Of the adult children, three (43%) were sons and four (57%) were daughters. One participant (7.5%) was a female cousin.

The ages of the spouses ranged from 47 to 78 years with a mean age of 63 years. The ages of the adult children and the cousin ranged from 40 to 59 years with a mean age of 49 years. A total of four study participants (31%) were male and nine (69%) were female. Participants identified themselves as members of the following ethnic categories: two (15%) African-Americans; eight (62%) Caucasians; two (15%) Hispanics; and one (8%) Asian-American. To capture ethnicity and family relationships together, one (8%)

spouse was African-American, two (15%) were Hispanic, and two (15%) were Caucasian. One adult child (8%) was African-American, one (8%) was Asian-American, and five adult children (38%) were Caucasian. The study participant who was the cousin (8%) was Caucasian. Based on these demographic data, maximum variation was achieved (Lincoln & Guba, 1985) through purposeful sampling procedures employed by the investigator.

As reported by the study participants, the number of children in each of the families of individuals with dementia ranged from no children to seven children. Fifty-one percent were females and 49% were males. Of the seven study participants who were caregivers for their parents, 57% were females and 43% were males. It is interesting to note that the two Hispanic wives in the study were married to much older men who had been married twice before. In these two cases, children from the husband's prior marriages were not involved in caregiving activities or decisions.

Four of the 13 study participants (31%) stated they completed high school and nine (69%) attended or completed college. Two (15%) study participants classified themselves as writers, two (15%) classified themselves as working in the health care field, five (38%) classified themselves as working in management, three (23%) worked in education, and one (9%) worked in the home.

The length of time each loved one had been cared for at home before the decision was made to place him or her in a LTC facility ranged from six months to five years. The average length of time a loved one with a diagnosis of dementia was cared for at home was 32 months or 2.6 years. The number of years since the diagnosis of dementia was determined ranged from 18 months to 6.5 years with a mean of 37 months or 3 years. The ages of the loved ones the study participants cared for ranged from 62 years to 89 years with a mean age of 78 years. Six (46%) were females and seven (54%) were males. The spouse caregivers in the study informed the investigator that they were in their first marriages (n=9 or 70%), in their second marriages (n=2 or 15%), or in their third marriages (n=2 or 15%).



Table 4.4 below presents the demographic data that describes the study group and Table 4.5 presents the demographic data about the relatives with dementia for whom members of the study group cared.

Table 4.4: Bio-Demographic Summary of Study Participants

Family Member (Decision-Maker) Bio-demographic Summary						
Relationship to Person with Dementia	N	Mean Age	Ethnic Identities	Mean School Years	Mean Years Care at Home	Familiarity with LTC
Wife	4	60.25	1 - African-American 2 - Hispanics 2 – Caucasians	12	3	3 - None 1 – Friends
Husband	1	74.00	1 – Caucasian	16	5	1 – None
Adult Children	3 - sons	49.00	1 - African-American 2 – Caucasian	16	1.5	1 - Family/Friends 1 - Self/Family 1 – None
	4 - daughters	47.25	3 - Caucasian 1 - Asian-American	16	1.8	1 - Self/Friends 3 – None
Cousin	1 (female)	59.00	1 – Caucasian	16	2	1 – None

Table 4.5: Bio-Demographic Summary of Individuals with Dementia

Demographics of Relatives (Loved ones) with Dementia					
Relationship to Study Participant	Wife	Husband	Mother	Father	Cousin
Mean Ages	71	74.5	82.75	82	74
Mean Years of Education	16	14	15	13	16
Mean Years Since Dementia Diagnosis	6	3	2.8	2	1
Mean Years Being Cared for at Home	3	5	1.5	2.3	2

### Central Findings: “Coming To Terms”

#### A Grounded Theory of Dementia Caregivers’ Journeys and Expectations of Care

“Coming to Terms” is a grounded theory of dementia caregivers’ journeys and expectations of care that is comprised of transitional stages and behavioral phenomena that were revealed in the narratives of the study group. This grounded theory reveals the family members’ journeys through various stages of their lives as caregivers including their limitations, increasing demands of continuing decline in their loved ones, challenges they faced, and decisions they made. Throughout stories of their journeys, the study

participants described increasing levels of awareness about limitations, demands, challenges, and decisions that needed to be made. Indicators and descriptions of “experienced awareness” of participants’ journeys illustrated in Table 4.1 and Figure 4.1, are presented as important transitions through the stages of “Coming To Terms.”

Revealed in the narratives of their journeys were five transitional stages through which they passed. Their movements in and through the five stages were influenced consistently by their own lived experiences as family members, caregivers, and primary decision-makers. The nine behavioral phenomena represent experienced awareness and the interpretation of caregiving experiences in the context of contrasting their abilities with growing care needs. The experienced awareness gave them direction throughout the five stages and provided them with tools to decide what needed to happen next.

The five transition stages (printed below in bold) and nine behavioral phenomena (printed in italics) of the “Coming to Terms” social process are:

**(1) Transitions to caregiver role**

*(a) Sees losses*

**(2) Takes on caregiver role**

*(a) Fills gaps*

**(3) Relinquishes caregiver role**

*(a) Recognizes limits*

*(b) Acknowledges need for LTC placement*

*(c) Responds to relinquishment of care*

**(4) Selects and evaluates LTC facility**

*(a) Makes selection*

*(b) Evaluates care*

**(5) Accepts LTC resident status**

*(a) Accepts LTC status*

*(b) Justifies LTC placement*

Figure 4.1 illustrates the emergent “Coming to Terms” grounded theory as a graphic model. Having witnessed their loved ones’ decreasing abilities to care for

themselves and having stepped forward to fill gaps by becoming caregivers, the participants in this study told how they consciously and unconsciously developed expectations of dementia care based on their own experiences. As the progression of the dementing disease took away more and more of their loved ones' cognitive and functional abilities, each participant took on increasing challenges and numbers of duties in order to keep the care recipient clean, healthy, happy, and safe. Most participants admitted that they had no formal training to rely on when deciding what care was needed, but they did not hesitate to formulate expectations of themselves in the context of wanting to do a good job meeting the needs of their loved ones with dementia.

In Stages 1 and 2, the expectations the caregivers developed were based on what they believed they had to do to care properly for their loved ones in light of the losses and needs presented. In Stage 3, the caregiving family members realized that the increasing demands for care presented by their loved ones with dementia were exceeding the abilities they had to deliver the care and remain healthy and intact themselves. In the process of realizing that they were unable to meet escalating levels of care, the participants began to entertain ideas and accept realities that they could no longer "do it all". Along with these increasing doubts and realizations, participants discussed changes in what they expected of themselves in caregiving roles and began to formulate expectations of care they would want their loved ones to receive from staff in a LTC facility when it came time for placement. Many study participants discussed having feelings of guilt as well as relief when they recognized they were having doubts about continuing to provide all the care. Many also acknowledged that it was difficult to admit their shortcomings and desire to relinquish all or some of the care.

In Stage 4, as the search for a LTC facility ensued, and Stage 5 after most loved ones were admitted to a LTC facility, the study participants continued to draw upon their own caregiving experiences in Stages 1 through 3 as points of reference for formulating and adapting expectations of dementia care they wanted staff at the LTC facility to provide. The analysis of data revealed that the family members expect six major dimensions of care to be provided by the LTC facility. They are: (1) all-round patient

care, (2) pleasant surroundings, (3) a competent staff, (4) a caring staff, (5) prompt communication of developments related to the loved one's condition or care, and (6) responsiveness to the family's questions and concerns.

Detailed Examination of the Stages and Behavioral Phenomena of  
“Coming to Terms: A Basic Social Process of Formulating Expectations of  
Dementia Care”

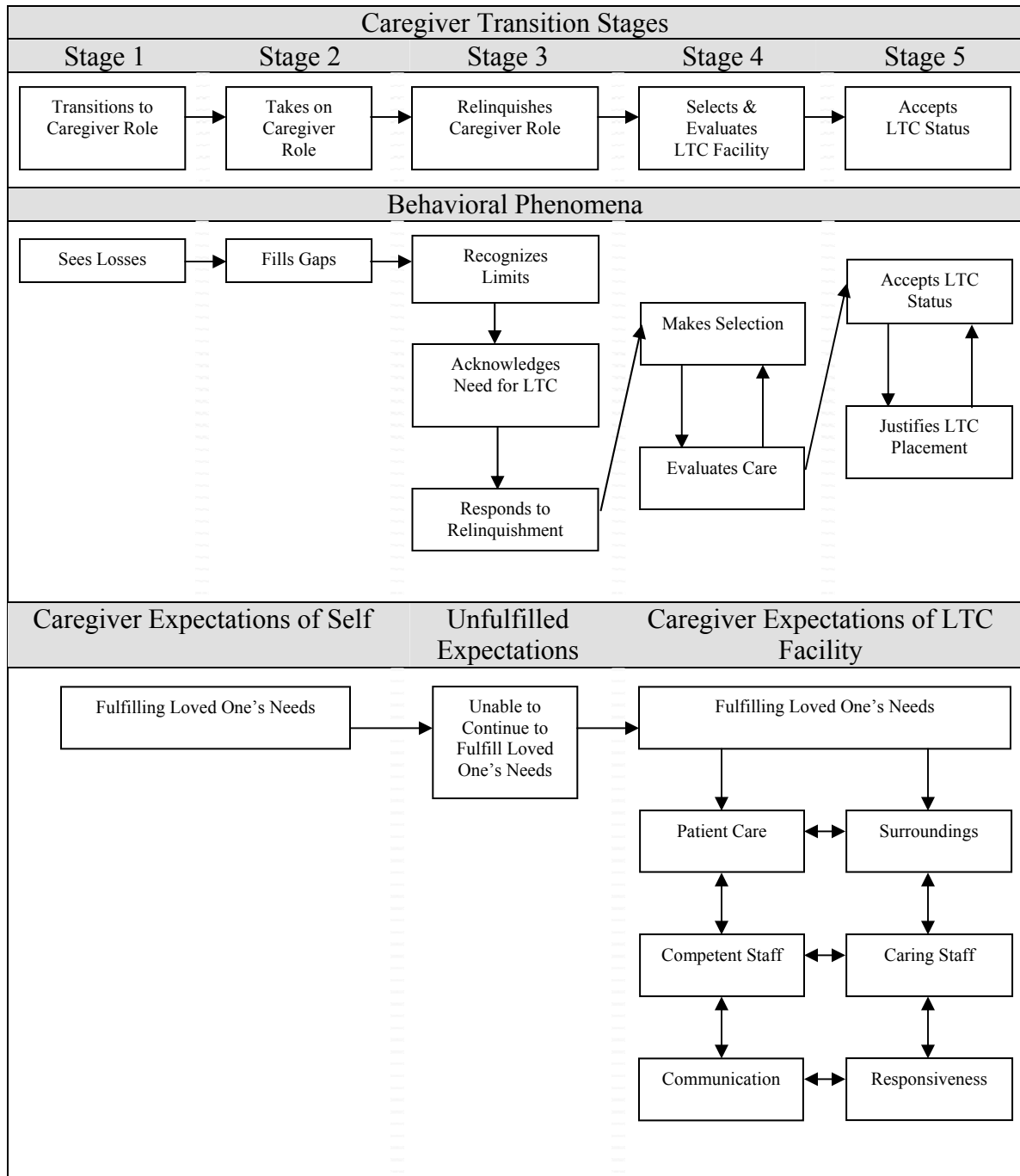
The narratives of the study participants demonstrated the existence of a common five-stage social process or transition model through which each person passed as he or she formulated expectations of dementia care provided by LTC facilities. The stages and the behavioral phenomena and expectations that accompany them are described in detail below. Notably, during the performance of member checks, study participants who were presented with this “Coming to Terms” model readily identified a stage that corresponded to their past and present experiences as caregivers and they verified and confirmed that the investigator's description and labeling of the stages were appropriate.

*Stage 1 –Transitions to the Caregiver Role*

In Stage 1, the family members transitioned to become providers of care after they noticed that their loved ones were losing various abilities to perform activities of daily living and other tasks, which he or she regularly performed independently in the past. As the family members came to terms with the changes and losses they were seeing, each one described what they thought they needed to do to compensate for the losses. In so doing, each family member began to formulate self-imposed expectations of the kind of care he or she wanted to provide for the loved one.

Figure 4.1: “Coming To Terms”

Stages in Caregiver Transitions and Behavioral Phenomena That Inform Expectations



Study participants reported basing their expectations of the care they would deliver upon the losses they observed and their continuing observations of things that were changing for the worse. In some instances, the changes they witnessed centered on the loved one's confusion or forgetfulness. One of the daughters noticed that her mother *"would be quite forgetful like that and just needed to be reminded of a lot."* (4.24). One of the wives in the study group recalled that *"sometimes [my husband] could not remember things"* (5.36). Yet another participant noted that his mother *"admitted she was very confused"* (4.7). In a worried state about her husband's safety, another one of the wives in the study group said, *when [my husband] wanted a cup of coffee... and if I didn't watch. . . . [he] would put a pot of water on the stove and let it burn"* (3.13).

In other instances, members of the study group expressed concerns when they noticed changes in their loved ones' sleep and activity levels. For example, a daughter remarked that her father *"didn't walk in the neighborhood as much"* (3.8) as he used to. Another respondent recalled that her cousin was *"fall[ing] asleep a lot"* and that *"she even flooded the house"* (4.13).

Declining abilities of loved ones to do self-care were seen by most all participants in the study group. This was evident to the caregiving cousin who noticed that *"[she] hadn't taken a shower for 2-3 days and had the same clothes on [that she had] 3-4 days earlier"* (4.17). One son reported that his *"mother went about five days without taking any food"* (4.1), and a daughter observed that her *"[father] was eating sometimes really bizarre things, so [she] had to keep an eye on him"* (4.31). One of the sons who feared that his mother's memory loss would cause her to take too much or too little of her prescriptions noted that, *"[my mother] spent a lot of time... writing down what medications she was taking and how much she was supposed to take"* (18.6-18.7). One of the daughters in the study group revealed her concern about her father's failing memory when she said he *"had to ask me is that the right way to write a check?"* (3.9).

As the family members identified their concerns and worries about their loved ones' losses, they began to realize that action on their part was required in order to

compensate for them. Thus, one daughter recalled coming to the conclusion that her mother needed more supervision with self-care activities she could not longer do. The daughter recalled saying, “*We can’t trust her to take meds [correctly]*” (4.3). One of the wives told the story of how she came to realize that her husband was becoming less and less able to do things for himself. She said, “*I had to begin to feed him*” (19.5) and “*I began to dress him*” (19.6). Similar self-care deficits were described by other family members when they recounted key situations that had awakened them to the realization that their loved ones were in trouble. A daughter recalled that, “*[T]rying to get [him] into the shower to get [him] cleaned up... was a real fight, a real struggle...*” (4.32). The instances of data presented above illustrate the types of experiences that alerted family members to failing memories in their loved ones. The instances are also the stimulating factors that family members responded to as they took it upon themselves to compensate for deficits and provide for the safety of their loved ones.

### *Stage 2 – Takes on Caregiver Role*

In Stage 2, the family members were actively engaged in caregiving roles. They took on those roles after seeing the losses in their loved ones and deciding that only they could compensate for those losses by filling gaps. As they saw more and more losses and determined more of what they needed to do to assist their loved ones, study participants continued to formulate and adjust expectations of themselves as caregivers. At this point in what emerged from the data as a transition process, caregivers were not aware that what they expected of themselves would soon be the expectations they would have for other care providers in other settings.

Initially in this stage, some family members began to assist loved ones with routine household chores in addition to helping with activities of daily living (ADLs). One wife acknowledged making the bed alone; a task that her husband used to help her do (19.9). The daughter who described her father’s changing abilities to balance his checkbook took on the tasks of paying his bills each month (3.10). The deepening degrees of concerns the family members experienced as more and more deficits were

noticed in their loved ones were revealed in one relative's story. When the loved one she was caring for did not answer the telephone when she called to check on her, she said, "*I went into a panic mode. So I called the sheriff to go out and check on [her]*" (5.23).

The diligence with which the family members tended to the needs and safety of their loved ones was very clear in this stage. The caregiving relative captured the tremendous commitments among the study group when she said that in addition to taking care of her own house, she was "*taking care of both of [my relative's] houses, [her] phone calls and making sure [she] gets to [doctors] appointments*" (5.30). One wife who previously was accustomed to being the passenger when she and her husband went around town or on trips said, "*I do all the driving for [him] now*" (19.8). More specific examples of types of care activities that family members described adding to their caregiving loads in this stage included preparing meals, assisting more frequently with basic hygiene, helping with toileting needs, and assisting with or administering medications.

Also during this stage, the deficits in ADLs took on new meanings for the study group. Not only did the deficits indicate to them that functional abilities were declining. They also meant that health and well-being were being compromised when the deficits were manifested. For example, a wife's awareness of her husband's inability to initiate responses to hunger spawned new worries of malnourishment. One of the daughters said that she would "*just check that [her father] was getting nutrition*" (19.7), while a diligent wife said she made sure that *[her husband] ate*" (19.11) (1.20). Participants' stories revealed they had advanced their caregiving responsibilities in Stage 2 to include "*fixing breakfast*" (19.9), *feeding* [their mates] (19.5) and *cooking meals*" (19.3).

To maintain proper nutrition, some participants made arrangements for meals to be brought into the homes of their loved ones. Two daughters said that they "*had Meals on Wheels for [their parents]*" (38.1) (38.5), and a husband revealed help he got for his wife's nutrition. He said, "*The board of deacons [at the church] brought a meal every week for about a year*" (38.3). Others members of the study group and some other family members cooked and provided meals to their loved ones. One of the sons remarked that



his “*brother would make sure [that their] mother had food*” (1.2) and another described how a different family member helped out by making “*lunch and supper for my mother*” (1.6 – 1.7).

Several respondents asserted they would assist with personal hygiene and dressing. Wives talked about “*bathing and cleaning my husband*” (19.9), “*helping him shower*” (19.8) (19.14), and “*having to dress him*” (19.6) (19.18). Other respondents talked about assisting with toileting activities. One daughter stated “*My father was incontinent for quite a while*” (4.26) and “*he had no control over his bowels. I had to clean him up after an accident*” (4.26-4.28). Toileting issues and accidents were frequent occurrences discussed by the study group. One wife stated that, “*Bowel movements became a problem*” (5.37). In response to increasing toileting issues, one of the husbands said, “*There were a number of messes to be cleaned up [in the bathroom]*” (18.18). One participant found that toileting needs disrupted sleep for both him and his loved one. He noted that he was “*getting her up every two hours at night to [take her] to the bathroom*” (1.13) to prevent accidents.

Finally, making sure their loved ones were taking their prescribed medications became an important endeavor for the family members. Several respondents emphasized they were having problems with their loved one consistently taking their medications. One son stated “*My brother could not get my mother to take medications*” (4.2) or, one daughter said “*We can’t trust [my mother] to take meds*” (4.3) (3.3) (19.2). One wife would “*give [her husband] his medications*” (19.9). Another wife replied “*I gave [medications] to [him]*” (19.2). Earlier acts of reminding loved ones to take their medications changed and became acts of delivering the medications directly to be sure they were taken.

Once a diagnosis of dementia was made by the primary physician, several family members felt the need to start learning more about dementia. They expressed this desire for more information in one of three ways by: (1) asking their loved one’s provider questions about dementia, (2) reading and/or looking up information about dementia on the internet, and (3) attending community dementia support groups. An example of the

first method of learning more about dementia follows. One of the wives who had just placed her husband in a LTC facility stated she received a bill from the nursing home charging a fee for the Aricept her husband was receiving. When she reviewed the bill, she thought it was a lot of money to spend and not see a difference in her husband's condition. She told this researcher she asked her husband's doctor if the medication was really helping her husband. The doctor stated "*It's not going to do your husband a bit of good. But if you want to give it to him, I'll be glad to write you a prescription*" (33.9). So, she decided "*Well, that was good enough for me*" (33.10) and her husband was taken off the medication.

An example of the use of the Internet to learn more about dementia was provided by a son who searched for information to help him come to terms with his mother's progressive illness. He said he learned that "*the less interaction a person has and the more they are just to themselves, the worse they get... mentally*" (17.5). It was clear by his comment that he had been reading about dementia. Another son who admitted he had been reading about dementia concluded that, "*...people with dementia need light*" (17.4) and "*...people with dementia need activities*" (17.2). The significance these enlightenments had for most participants was found in the formulation of their expectations of themselves as caregivers and care providers in LTC facilities. One of the wives who used the Internet to, "*learn everything possible about [dementia]*" (16.2) said that she also took the advice of a social worker and "*called the Alzheimer's Association*" (16.4) to learn all she could.

Finally, two family members attended community support groups as a way of learning about and understanding how to cope with their loved one's illness. To cope with feelings about caring for a loved one at home, one participant started taking his loved one to a community day care center and eventually joined the dementia family support group. "*I was taking my [relative] to the day care center two days a week for one and a half years before I placed her [in a LTC facility]*" (38.4). It was while attending a support group meeting that he found out about this study and decided to participate by saying if his story and experiences could help others, it would be worth it.

The 54 year-old daughter of another nursing home resident stated she had heard about the support group when her father had attended a few day care activities at the center. She also expressed an interest in participating in this study while attending the community support group for family members with loved ones with dementia.

It was clear that while the family members were ‘filling the gaps’ in the care their loved ones were unable to do for themselves, they realized that they were fully entrenched in all-consuming caregiver roles without much if any help from other family members. During this stage, expectations of the types and levels of care the family members needed to provide for their loved ones began to take more definitive forms. Not only did the family caregivers realize that care demands were increasing as time went on, but they also realized that the care they were giving was now required more fully, regularly and repetitively. For example, new or revised methods of supporting the nutritional needs of a loved one came about when increasing losses meant that feeding activities had to be added to what started out as a simpler task of providing a ready-to-serve meal.

As care demands increased in depth, breadth, and frequency, study participants more clearly delineated the expectations they had for themselves as care providers and at the same time, rather unconsciously, began preparing expectations that would transfer to others who might eventually help with or assume caregiving responsibilities.

### *Stage 3 –Relinquishes the Caregiver Role*

In Stage 3, members of the study group of caregivers were found to recognize their limitations and realize their inability to continue to meet the ever-increasing demands for care. In this Stage, the caregivers processed the decision to relinquish their caregiving roles after carefully weighing the care needs against their abilities to deliver what was needed. Caregivers acknowledged time was getting close when LTC placement of their loved ones must happen. Once the caregivers moved toward acceptance of this necessity, they grew more comfortable with the idea that they knew the care that needed

to be provided and that they could find a facility whose staff would meet their expectations.

The family members' realizations that they were at a point where they could no longer provide care for their loved ones rose from different perceptions and were influenced by several factors. One contributing factor found in the narrative of a daughter revealed that her mother was hard to get along with. She said, "*[She] can be pretty obnoxious*" (7.9). Frustration in the voices of most participants in this stage of their 'Coming to Terms' journey was heard when, for example, a daughter remarked that, "*The caregivers are trying to do what is best for my mother, but my mother is really pushing her [caregiver][beyond her level of tolerance]*" (7.5).

A factor that influenced the relinquishing of care by family members in the study group was the stress they felt in a variety of situations. One son acknowledged that he "*was not coping with [his mother] being at home*" (7.1) and said "*There was increased stress on [the caregiver]*" (7.4). One participant in the study group felt "*stressed... stressed to the limit [while] trying to take care of . . . her house ... and that of her loved one...*" (7.20). While one son stated, "*My mother needed more attention than [we] could give her [at home]*" (5.2), other caregivers cited their own poor or declining health conditions as reasons to place the loved one in LTC. For example, one of the caregivers said, "*I have a lung condition and... it is difficult for me to get around anymore*" (7.14) (7.16). A realization that the loved one could no longer remain safe, alone in the home, drove many family members to the final decision about finding a LTC facility. Some participants were especially concerned about leaving the loved one home alone (5.7) and another admitted that she "*could no longer handle [her husband] at home*" because "*he was too sick*" (5.35).

In some cases, members of the study group were influenced by other family members to relinquish care for a loved one. Several participants stated that their relatives influenced their decision to relinquish care, but each stated that the final decision was theirs. "*My kids pushed me... but, I made the decision*" (9.12-9.14) said one of the husbands. One wife stated "*I have only two [children] and [they] said that [their father]*

*needed to be in a nursing home because [they] thought it was too hard on the family”* (9.17). One wife revealed that her adult children influenced her. She said, *“My children approached me that they thought [my husband] needed to go to a nursing home”* (9.30). One son caregiver said, *“with [my father] being terminally ill ... [we] all thought it was best for [my mother] to go to a LTC facility”* (7.12).

Health Care providers also influenced the decision for some of the participants. One wife was advised by her doctor to place her husband in LTC because he *“required 24/7 care”* (7.19). One of the sons said that his mother’s doctor believed, *“she would probably be better off”* in a nursing home (5.4). The caregivers’ decisions to relinquish care to someone else did not seem to be a snap decision. Vacillation whether to continue providing care at home or to seek LTC care was common, even after the loved one had entered the LTC facility. Several respondents expressed feeling guilty about making the decision to relinquish the caregiver role. *“I feel guilty... did I make the right decision...?”* (11.3) (11.5) (son). One of the daughters admitted, *“I do have my moments of guilt”* (11.17). A husband in the study group was struggling with his decision, long after the fact. He said, *“I frequently will feel guilt-ridden and think I really ought to bring her home”* (11.21). One of the wives who was still suffering from unresolved feelings about admitting her husband to LTC said, *“I called people... then I sat up and cried”* (11.25) and *“of course, I still cry a little”* (11.19).

Rather than experiencing feelings of guilt upon placement in LTC, several other participants, including husbands, sons, and daughters, said they felt relieved. Comments ranged from, *“...I guess I’m very much relieved”* (11.37), to admissions that lowering levels of stress were positive actions. As one participant said, *“...my stress improved and [I was] pleased and proud that I had done the right thing”* (40.1).

Up to this point in the “Coming to Terms” model grounded in the participants’ narratives, care expectations of family members centered on the personal needs of the loved ones, ADLs, and instrumental activities of daily living such as house cleaning, maintaining finances, and providing transportation to and from appointments. Eventually, as the loved ones began to demonstrate greater needs for assistance with meeting

nutritional needs, attending to personal hygiene, toileting, and taking medications, realizations that other arrangements for care must be put into place consumed the thinking of the study group members.

During all of their caregiving activities and their realizations that other forms of care and other care providers were needed, family members continued to formulate and cultivate expectations of the care they wanted for their loved ones. Accordingly, even though the family members in Stage 3 realized they were unable to continue performing caregiver roles, the expectations of care they had for themselves became the basis upon which they built their expectations of institutional LTC for their loved ones with dementia. In Stages 4 and 5 described below, family caregivers transitioned to performing activities that involved the selection and evaluation of LTC facilities that were or had the potential to be places where their loved ones would reside.

#### *Stage 4 – Selects and Evaluates a LTC Facility*

In Stage 4, the family members transitioned to selecting and evaluating LTC facilities that might become the residences of the loved ones they could no longer care for at home. Having relinquished their caregiver roles and having accepted the fact that other care providers were necessary to find in order to ensure the well-being of their loved ones as well as themselves, family members moved into action to select and evaluate several LTC facilities.

During this transition stage, caregivers were found to call upon the expectations of care they developed for themselves in Stages 1 and 2 and the limitations they realized in Stage 3, to prepare care expectations they wanted LTC facilities to meet. Early in Stage 3, care expectations were limited to the care activities the study group experienced providing such as nutrition, help with personal hygiene and toileting, and taking medications. However, during Stage 4 and throughout Stage 5, when selection, evaluation, and acceptance activities were fully engaged, five additional expectations of care were formulated. Now, in addition to the expectations of care relating to the fulfillment of the loved ones' basic needs described above, the family members

transitioned to add expectations of pleasant surroundings, a competent staff, a caring staff, institutional communication, and institutional responsiveness. The additional expectations arose out of plans to hand over care of loved ones to places and in conditions where family members had little control because they were occurring away from a family home and involved activities performed by persons other than family caregivers.

The six categories of family expectations of dementia care became the operative concerns of the study group members throughout the remainder of their transition experiences involving the admission and continuing care of their loved ones in a LTC facility. The family members used all of these expectations in Stage 4 as the basis for selecting the facility and they continued to use them in Stage 5 to assess the facility where the loved one had been placed.

The six categories of expectations of dementia care are not rank ordered. It was not the purpose of this study to determine whether one category of expectations was more important than another. Thus, nothing should be drawn from the order of the expectations in the discussion of them below. The order simply reflects the order of their appearance in the model illustrated in Figure 4.1 (p. 64).

#### Detailed Discussion of Six Categories of Expectations of Dementia Care

##### *Expectation of Patient Care: Fulfilling the Loved ones' Basic Needs*

The data from the narratives demonstrates that the expectation of patient care, which will fulfill the loved one's basic needs, includes (1) providing proper nutrition, (2) helping with personal hygiene, (3) assisting with toileting activities, (4) assuring the loved one took prescribed medications, and (5) making sure the loved one participated in physical and cognitive activities.

##### *Providing Nutrition.*

Providing for and maintaining the loved one's nutritional status was an important expectation of dementia care. It was expressed in the narratives in three ways: (1) being

served a healthy diet, (2) assisting resident with setting up and eating meals, and (3) maintaining family traditions. Some participants expressed the expectation that the LTC facility would provide healthy meals. One son maintained, *“I want [my mother’s] food to be nutritionally appropriate”* (10.18). The participant wanted the staff to *“...make sure [my loved one] was eating a healthy diet”* (10.103) and one of the wives said she wanted her husband *“...to be fed ... to be well fed”* (10.135). Eight of the thirteen participants had expectations related to helping the loved one with meals.

Maintaining family traditions related to eating and mealtimes concerned several participants. One participant asked that his loved one’s tradition of drinking tea and taking a glass of wine before dinner be observed. He said he told the staff, *“[My loved one] is a big tea drinker. They keep [her] going with the tea”* (10.78), participant *“...and we always did have a glass of wine before dinner every night...I would like that to continue if possible”* (10.77). Another participant, one of the sons, expected that his mother would *“get [her] three meals [a day]”* (10.51).

It is evident from the family members’ responses that paying attention to the loved one’s nutritional status was an essential expectation of LTC care, which was rooted in the family members’ traditions as well as experiences and personal expectations in the earlier stages of the “Coming to Terms” process when direct care was being delivered by the family members.

#### *Helping with Personal Hygiene.*

The family members expected the LTC facility to help their loved ones with personal hygiene. The narratives demonstrated three principal concerns: (1) assisting with personal grooming, (2) assisting with bathing and overall cleanliness, and (3) assisting with dressing and maintaining clothing. One participant specifically expected grooming to be part of the loved one’s LTC care. He had asked the nursing staff to be sure they *“cleaned [my mother’s] face after eating”* (10.5). He continued to say, *“I expect that [my mother’s] hair is groomed and combed each day and when it is messed up”* (10.9).



While the other the respondents did not specifically refer to assisting with personal grooming, overall cleanliness was expected. Two sons and two wives made comments referring to overall cleanliness. A son said, “*I expect that my mother is kept clean*” (10.8), “*...as clean as possible*” (10.59), and a wife remarked that she wanted her husband “*to be clean*” (10.125). Others expressed the concern that the loved one bathe and be free of odors. One wife and one son were adamant that “*I should never come [to the LTC facility] and smell [my husband] before I got there*” (10.94). A son wanted to make sure “*there was no smell of urine*” (10.7) on his mother or in her room. One daughter replied “*If [my mother] dirties [herself]...I expect her to be cleaned up*” (10.28).

Several participants expected that their loved ones have their own clothing available to wear (10.113; 10.19). Other responses demonstrated that family members expected their loved ones to be properly dressed. One wife was upset as she recalled the story of the day she visited her husband and found, “*he had his pajamas on. . .[and] that is not acceptable*” (14.29).

#### *Assisting with Toileting Activities.*

The loved one’s inability to attend to toileting activities was one of the reasons the caregivers cited for relinquishing the caregiver role. The narratives demonstrated that the provision of assistance getting to the bathroom remained an expectation once the loved one entered the LTC facility.

The family members expected their loved ones to be assisted to the bathroom whenever indicated. One son wanted the staff to know about his mother’s incontinent episodes, expecting that “*[she] would be cared for in [her] level of incontinence*” (10.43). One wife and one daughter expected the LTC facility staff to “*...take [my husband] to the restroom*” (10.83) and “*Help [my father] to the bathroom*” (10.127).

*Making Sure Loved ones Take Their Medications.*

A number of participants expected the LTC facility to make sure their loved ones took their prescribed medications. Family members wanted health care professionals to administer the loved ones' medications to ensure their proper delivery and monitor their loved ones' responses to their medications. One wife stated, "*I want the nurses to give my husband his medications*" (10.122). One son and one daughter maintained that licensed personnel must "*oversee the giving of medications to see that they are given properly*" (10.56; 10.32). Other participants also described medication delivery and monitoring as a very important expectation of LTC. A cousin said, "[I] *expect them just to monitor [my loved one] and make sure [she] is taking [her] medications*" (10.96).

*Making Sure Loved one Participates in Physical and Cognitive Activities.*

Finally, family members expected the LTC facilities to provide physical activities to maintain physical function and cognitive activities to stimulate the mind. Three wives replied "*I want [my husband] to have therapy*" (10.134), "*I want [my husband] to participate in therapy*" (10.121), and "*...get [my husband] to do some type of exercise*" (10.85). Some of the participants stated they noticed that the LTC facility did not seem to have enough physical activities for their loved ones and stated they would like to see more activities offered. One said, "*I'd like to see more outings*" (10.70).

Other respondents remarked approvingly that the LTC facility provided time for physical activities. They felt the LTC facilities were meeting their expectations that their loved ones be consistently engaged in some physical activity to maintain function. One husband stated, "*[They] do exercises in place*" (30.9) and "*...they would go down to the park and walk around*" (30.7). One wife was pleased to note that her husband liked the physical activities. She stated, "*[He] likes to get involved in the recreation activities on the unit*" (30.17). One daughter was pleased that the LTC facility would "*...take [my father] to senior night out every month*" (30.5) and "*... take them to lunch at a restaurant somewhere*" (30.6).

Indeed, physical activity was deemed so important that some of the respondents took it upon themselves to provide it. One wife acknowledged taking her husband out for some exercise. She stated “...*we’re going to go out and we’re going to get a little exercise and you’re going to do a little walking*” (10.101). Family members also expressed a desire to see cognitive activities scheduled for their loved ones. One son wanted “...*to get [my mother] to think, to be able to process, to keep [her] mind working*” (10.45). He also expected the LTC staff to “... *to be able to give [her] some time to where [she] was compelled to talk, to converse*” (10.54). A different son stated, “*I would like to see [my mother] interact more with the other people...*” (10.62). Also, one daughter had suggested activities like “*playing word games, playing cards, and writing letters*” (10.64).

Other respondents acknowledged that the LTC facility provided cognitive stimulation activities for their loved ones. They asserted that LTC facilities were addressing their expectations that their loved ones engage in activities to stimulate their minds. For example, a husband was pleased that “*they had things to color and they had little quizzes*” (30.8). One wife stated “*they have jigsaw puzzles out in the lobby for them to work on*” (30.21), and another wife noted that her husband participates in “*the activities like bingo and music*” (30.20).

Family members expected their loved ones to have opportunities to engage in both physical and cognitive activities. Accordingly, the provision of such opportunities was an important factor in the family members’ assessment of LTC facilities providing dementia care.

#### *Expectation of Pleasant Surroundings*

The second category of expectations of dementia care that emerged from the narratives was that the family members wanted a LTC facility with pleasant surroundings. Family members sought out facilities that were clean and free from unpleasant odors and had both private and public spaces appropriate for the resident.

Cleanliness was an important criterion in the family members' evaluation of LTC facilities. A son in the study group remarked "*what impressed me the most is that the building was clean*" (10.6). Another son noted the nursing home "*seems very clean*" (13.5). First impressions mattered. One respondent who had placed his mother in a LTC facility stated that one of his criteria for selecting a nursing home would be "*one that is real clean to me [when I go] in the main entrance*" (10.39).

Along with cleanliness, respondents desired a facility that was free from odors. A daughter in the study group noted that the nursing home "*...wasn't dirty, but it didn't seem as clean as it could be either...although there were no odors or anything like that*" (13.36). A wife praised a LTC facility because "*it doesn't have the usual odors you think are associated with older people of urine and disinfectant*" (32.33).

Family members also evaluated LTC facilities based upon the appropriateness of the private and public spaces where the residents lived. Some study participants made visits to several LTC facilities before making their decisions. While visiting the facilities, family members would examine the room where their loved one would live. One son wanted to know "*what type of room [would] my mother be in?*" (14.8). He also went on to ask "*Does the room look like rooms where there is a comfort level for my mother?*" (14.7). When the husband of one of the residents was contemplating placement, he stated "*...it was not ultra fancy*" (13.11). However, he went on to say "*I got permission to look into the rooms that were already occupied...and the beds were made...*" (32.18). One son observed that "*My mother's room could be larger*" (10.22).

The family members' impressions of the LTC facilities' public spaces also factored into their evaluations. Family members expected these spaces to enhance the quality of their loved ones' living experiences. Some study participants reacted positively to the public spaces they viewed. One husband remarked "*the common rooms were airy and had lots of easy chairs for...for people to sit and watch TV*" (13.12). Another participant recalled that the nursing home she was considering for her loved one was "*exceptional*" (32.22) and that everything was under one roof and "*it looked like resort living for senior citizens*" (32.24).

Other family members reacted negatively to what they saw as they visited LTC facilities. When one son visited a nursing home, its public spaces caused initial concern. He noticed “*the unit was not well lit and that caused me to have a negative impression*” (13.3). A wife reacted negatively to a nursing home’s common areas, recalling “*there were gnats flying around; the floor [was] nasty*” (13.21). In both instances, the study participants made comments to administration and their concerns were addressed.

#### *Expectation of competent and knowledgeable staff*

Family members wanted their loved ones to live in a LTC facility where knowledgeable and competent staff worked. Family members expected the staff to have knowledge and skills related specifically to the care of individuals with dementia and knowledge and skills related to the care of LTC residents generally.

When evaluating staff’s knowledge of dementia care, some family members drew upon the knowledge they themselves had gained about dementia care in Stage 2 as they were “Filling the Gaps.” For example, the 44 year-old son who had placed his mother in a LTC facility felt the staff was not too familiar with the care of the demented patient. He stated “*I wish [the] staff would be more knowledgeable of [dementia]*” (10.21). He went on to say that “*I want [the] staff to be aware of the care of a person with dementia and keep that in mind*” (10.17). After his mother was admitted, he noticed the area where his mother lived did not have good lighting. He noted “*[the] unit was not well lit*” (14.4) and he based his criticism on his understanding that “*people with dementia need light*” (17.4). Similarly, a wife who had engaged in extensive reading about dementia stated “*[m]y husband has [dementia] with a lot of medical problems, so he needs a place that targets [dementia] and I’m looking for a facility that will meet the needs of my husband’s dementia as well as his medical problems*” (17.19).

Other family members knew through their own readings and experiences that people with dementia need supervision. Therefore, there was an expectation that the staff be aware of safety issues. One wife stated, “*I never want him to be in a room by himself unattended*” (10.87) and “*I didn’t want him to be alone*” (20.17). Another wife of a

resident who was recently admitted to a nursing home stated that she wanted the staff “*not to let him wander off*” (10.136). One daughter wanted her father to be supervised by the staff “[*to make*] *sure he doesn’t fall*” (10.104).

The family members also recognized that it was important that LTC staff be competent to address problems that were prevalent in LTC patients in general. A son, who was still trying to decide about LTC placement for his mother, stated that he wanted the staff to “*keep up with her blood pressure*” (10.46) and “*keep up with her heart rate*” (10.47). He also wanted the staff “...*to administer medications at the right time...and properly*” (10.49 & 10.52). A daughter expected the staff to know how to care for her mother if she became immobilized. She said, “*If my mother is bedridden...[I expect] that she will be turned and that she doesn’t develop bedsores*” (10.29).

#### *Expectation of Caring Staff*

The family members wanted to select a LTC facility that had a caring staff. Their expectations of a caring staff included treating their loved ones with dignity and respect as well as keeping their loved ones free from neglect and abuse. The 44 year-old son of one resident stated, “*I want my mother to be treated with dignity*” (10.15). His concern of his mother “being treated with dignity” may also be extrapolated from his expectations of patient care associated with nutrition, hygiene, and toileting. Comments such as “*I expect my mother is kept clean*” (10.8) and “*I want her clothes to remain with her*” (10.19) are manifestations of this participant’s desire that his mother maintain her dignity.

A daughter, who was having a hard time making the decision to place her mother in a LTC facility, conveyed concerns that some nursing homes near her home failed to treat their residents with respect. She recounted stories from others that some of the residents of those homes were not treated well. She had heard that “*everybody [was] doped up on neuroleptics and left in the hallway, lined up*” (21.12). She stated, “*I expect my mother to receive respect as a person*” (10.31). This affirmation was consistent with the participant’s expectations in regard to personal hygiene that “*[i]f my mother dirties herself...that she gets cleaned up*” (10.28).

The wife of a LTC resident was troubled because “[w]hen I go to the nursing home, I don’t see the love” (14.19). She explained, “I’ve read about [dementia]...they still have the function...don’t treat him like...they’re not just anybody” (17.18).

Other family members stated they did not want their loved ones neglected or abused. The same daughter who was having a difficult time deciding to admit her mother was adamant that her mother not be neglected: “I just don’t want my mother to [be] neglected” (10.38). Again, her concerns were amplified by stories she had been told. She had heard that “they line them up, dope them up, line them up in chairs, stick them in the hallway and [the patients] beg people to talk to them when you walk by” (21.1).

Similarly, another daughter who had been involved in the decision to admit her father to a LTC facility recalled “hoping that he just wouldn’t be lost in the nursing home and just kind of set up in a chair and forgotten about” (10.143). A son who was having a hard time with the decision to place his mother expressed concern about neglect, stating, “[I don’t want her] to go too long in embarrassing situations or situations that lead to more health problems or infections or something of that nature” (10.44).

Family members expressed their concerns about patient abuse in both general and specific terms. A daughter said, “I just don’t want my mother to get abused” (10.38). Two other respondents addressed more specific types of abuse. A son who had placed his mother in a nursing home asserted, “I do not want my mother to be physically abused” (10.14), and one of the wives expected the LTC staff not to be verbally abusive to her husband, expressing the hope “that nobody is ugly to him” (10.140).

### *Expectation of Communication*

The family members expected open lines of communication between themselves and the staff at the LTC facilities. Family members expected prompt communication related to their loved ones’ condition and care. One wife, whose husband was in a nursing home, responded by saying she wanted the staff “to call me or talk to me” (27.26). A husband who had been caring for his wife about five years at home before placing her in a nursing home, stated “I would expect them [the staff] to tell me anything

*they are allowed to tell me*” (27.11). He also expected the staff to talk with him “*if I happen to call them and ask them something*” (28.4). Another wife, whose husband was about to be admitted to long-term care, noted the importance of promptness and wanted the staff “*to call me at home*” (27.23).

The expectations of communication were built upon what the family members wanted and needed to know and when they expected the desired communication to occur. Some of the family members discussed their expectations of the substance of staff communications in general terms. Examples include reporting a change in the patient’s condition as well as normal updates. One son who had been having difficulty making his decision about placing his mother wanted the staff “*...to feel... if...there was anything important for the family to [know], they [the staff] would contact me no matter when or where or whatever time*” (27.1). A son who placed his mother in a nursing home remarked after she had been there for about two weeks, “*I expect them [the staff] to communicate [with me] if something happens to my mother*” (28.3). The family member who had been caring for her loved one at home for about two years and had not made the final decision for placement remarked, “*I don’t think the staff needs to communicate with me as long as everything is going smooth*” (27.16).

Other family members were more specific about what they wanted communicated about their loved ones in the LTC facility. One woman, who cared for her husband at home for four years before making the decision to admit him to a nursing home, wanted the staff to let her know “*if he was giving them any sort of difficulty*” (27.28), “*if he wasn’t eating*” (27.29), and “*if he wasn’t sleeping at night*” (27.30). One daughter had assumed the care of her father at home because her mother was unable to cope with her husband’s dementia. She admitted her father to a LTC facility when his dementia had become so bad that he was unable to remain at home. The daughter felt the staff should let her know about his mental status. She stated “*I think they should let me know...what kind of problems he’s dealing with mentally*” (27.20). Another daughter, who had assisted with her father’s care at home before he was admitted to the nursing home, had to be informed “*how he’s socializing with others*” (27.33) or “*how he’s eating*” (27.33).



When family members were asked when they thought communication should occur, the comments, again, ranged from general to specific. A gentleman who had placed his wife in a community nursing home, expected the staff to contact him “*anytime there [was] anything to communicate*” (28.6). The woman who was trying to make the decision to place her cousin stated, “*I feel the only time [staff] need to consult with me about anything is if they’re troubled about something ... and they can’t seem to resolve it*” (29.3). The son, who was still trying to make his decision, stated that “*if [he] needed answers to questions*” (28.2), he expected to “*get to the right person in a reasonable amount of time*” (28.2). When one woman, whose husband was in a nursing home, was asked when communication should occur, she replied, “*when they need to*” (29.5).

When other family members were asked about when communication from the nursing home staff should occur, they were more specific. The middle-aged son of one resident stated “*I expect the nurse or doctor to call me when there is a change in her condition*” (10.10). The daughter, who made the decision to place her father, wanted the staff to call her when her father was “*having problems either medically or mentally*” (28.9). The third wife of one of the residents expected the “*nurses should call whenever there is an emergency*” (28.12). She also expected that “*the doctors should call to tell me how he is doing and [tell her] about his medications*” (28.13). A wife who had placed her husband in long-term care added that “*it seems to me that [communication] ought to be at least monthly,*” (28.15) after she stated she expected the staff to let her know what her husband was doing. Finally, one of the daughters, who assisted with her father’s care before going to the nursing home, stated “*I guess it would be kind of nice to have some kind of update*” (27.32) after the doctor had visited with her father on his routine medical visits. The fifty year-old son of a resident in a nursing home was a notable exception. Asked when he expected the staff to communicate, he replied, “*Never*” (29.2).

#### *Expectation of Institutional Responsiveness*

The sixth and final category of expectations of dementia care that emerged from the narratives was that the family members expected the staff to be responsive to their

questions and concerns. There was no difference in the approach between the children or the spouses. Each study participant expected their concerns or questions to be handled promptly and by someone in authority. Asked how they would address or respond if their expectations of care for their loved ones were not met, the family members stated they would be willing to approach someone in an administrative position. Most stated they would start at the unit level. Many family members identified specific types of staff members at this level whom they believed had the responsibility and authority to deal with their questions or concerns. If these questions or concerns were not addressed to their satisfaction, the family members resolved to take them to a higher administrative level. Some were also willing to make their voices heard at the state or national level if necessary.

When asked whom they would approach if their expectations of care were not met, the respondents who had not yet placed their loved ones in LTC care identified the persons whom they would address in more general terms. The forty year-old daughter, who was still trying to make the decision to place her mother in a nursing home, replied that *“we would attempt to talk to whoever was in charge”* (22.2). The son, who was trying to make the same decision, expressed the same feelings. He responded, *“I suppose I need to be talking with whoever was in charge of the floor”* (22.4). Of the respondents whose loved ones were already in LTC facilities, only one answered in such general terms: *“I think I’d start with whoever was in charge of the unit at the time”* (22.45).

Respondents with loved ones in LTC generally answered the same question more specifically. Two different wives, whose husbands were residing in nursing homes, answered respectively: *“I would call the charge nurse”* (22.37); *“I would talk to the charge nurse”* (22.39). Another wife replied *“I’d talk to the administrator”* (22.41). A participant, who had cared for his loved one at home for about five years, had faced such a situation. He stated, *“I told the administrator in each case”* (22.11) He also noted that if his concerns were ever not addressed and not resolved to his satisfaction, he *“would just have to move her [to another LTC facility]”* (22.12). A son, who had just placed his mother in a local nursing home, replied, *“I guess I would complain first to the head*

nurse” (22.7). Another son, who had also admitted his mother, said, “*I expect the nurse or doctor to respond to my questions*” (10.11).

A wife who recently admitted her husband to a nursing home had a plan to handle her questions and concerns. If she identified a problem with the care provided, she would first approach the staff taking care of her husband. She started by saying “...*my first thing is I go to the staff nurse*” (22.21). She then said “*if I feel like that nurse is incompetent, I’m going straight to administration*” (22.22). “*I don’t want to waste air... I need to talk to somebody that can get something done...*” (22.25). If her concerns were still not addressed and resolved, she asserted “*I’m going to write a letter to [my] congressman*” (22.17) and “*I will go all the way to Washington, D.C.*” (22.32).

Others also expressed a resolve to go to a higher level if necessary. One son stated, “*If I weren’t satisfied, then I would go to the director of the nursing home...*” (22.8). Another son responded by saying, “*I would need to be talking with whoever was in charge of the facility*” (22.5). One daughter asserted, “*I guess if I didn’t get adequate answers...I’d probably go to the administrator*” (22.47). Thus, family members expected the staff at the LTC facility to be both responsive and prompt in answering their questions and concerns and most were willing to proceed to higher levels to ensure a satisfactory response.

#### *Stage 5 – Accepting LTC Status*

In Stage 5, the family members arrived at accepting the LTC status of their loved ones and, contemporaneously, used their loved ones’ LTC status to justify their decisions to place them in LTC facilities. The expectations of care developed in Stages 1 and 2, the inability to meet increasing care demands in Stage 3, and the development of newfound expectations in Stage 4 highlight the harsh reality that the loved one’s dementia had reached a point of no return. Placement in a LTC facility was the only realistic option. One wife, who described herself as very close to her husband, realized she could no longer provide the care her husband desperately needed, given his disease and its affect upon her own health. She stated, “*I have some medical ailments*” (7.18) and the social

worker and the doctor “*told me he required 24/7*” (7.19). She eventually accepted that her husband was going to have to remain in a nursing home because she said “*I wish I could keep him [at home], but I can’t; I can’t take care of him anymore*” (44.7a).

A participant who had been taking care of her husband at home for about four years remarked that “*cleaning him up had gotten to be a real problem*” (7.29). She relied on her children to help her make the decision to place him in a nursing home. She said “*...the children had talked about [nursing home placement], whether I could handle it... whether I could continue to take care of him...*” (7.30). She finally accepted her decision with the support of her children and admitted her husband to a nursing home close to her home. She accepted her decision by replying “*It’s sort of hard not to be the caregiver, but the fact I get over [to the nursing home] to see him frequently, I can cope*” (44.12a).

In making nursing home placement decisions, family members expressed feelings of unease and guilt. To alleviate these feelings, family members would strive to look at the losses the loved one had experienced as well as their own inability to provide care as valid justifications to seek LTC placement. One son, who had admitted his mother, asserted, “*I feel guilty*” (11.3) and he asked himself “*Did I make the right decision to bring her to [the] nursing home?*” (11.5). He justified his decision by claiming “*We had no other choice*” (7.3) because “*my brother was not coping with her being at home*” (7.1) and “*there was increased stress on my brother*” (7.4). Therefore, we thought our “*mother would be better off in a nursing home*” (7.2).

As awareness of the extent of the loved one’s inability to function crystallized, the family members realized that a life-change had occurred for the loved one and the family member alike. One son, who has been struggling with the decision to place his mother in a LTC facility, had concerns that he would not make the right decision. He responded to making the decision by saying “*It’s definitely a life change*” (44.3a). He went on to say “*If you can’t give them the care yourself, that you try to find as close to the best care you can...*” (44.3b).

As Stage 5 reached conclusion, the loved one’s LTC status and the losses they had were now fully accepted by the family members and were used to justify permanent

placement of the loved one in a LTC facility. A participant reflected, “[W]hat got me really concerned [was] about what would happen if I was in the hospital and my daughter was not here to take care of her?” (7.17). He experienced “a lot less frets” (44.6a) after he placed his wife in LTC. He responded to how he was doing at the time by saying “I guess the biggest concern that people have in my situation is that they are dumping on somebody else” (44.6b). He eventually justified his decision by saying “I think she is as well off there as she would be here... so, I keep telling myself everything is really all right” (44.6c). A daughter, who placed her father in a long-term care facility, reached a similar conclusion, saying “I know he is better off in a nursing home because I know he can’t live alone” (44.9c). The son who noted that his mother’s LTC placement would be a “life change,” likewise justified it because “that way someone will take care of her...” (7.11).

Notably, the six expectations of dementia care, discussed as part of Stage 4, were important to several processes that contributed to the grounded theory, ‘Coming to Terms’. As revealed in these findings, expectations of care also served to evaluate LTC services and justify why placement of loved ones was necessary as the dementia disease progressed. The family members used their expectations of patient care, pleasant surroundings, a competent staff, a caring staff, communication, and institutional responsiveness to continue assessing and evaluating the facility where the loved one was placed. Indeed, these expectations assisted the family members with completing the transition experience. Two wives admitted their husbands to a LTC facility after each had cared for them for about two years at home. Both justified their decision for placement because they felt comfortable with the nursing home itself. One stated, “I know this nursing home will be here for him and take care of him” (44.10) and the other wife asserted that “this [nursing home] [has] an excellent program because it is helping him and helping me” (44.11). These responses suggest that ultimately it is the satisfaction of expectations by the LTC facility that allows the family member to fully justify the decision to place the loved one in a LTC facility.

## Summary

The findings of the grounded theory study presented in this chapter are in two forms. The first was an emergent theory titled, “Coming to Terms”: A Grounded Theory of Dementia Caregivers’ Journeys and Expectations of Care that is displayed and described as a model comprised of five stages and nine behavioral phenomena that are grounded in the narratives of a study group of family members experiencing the placement of a loved one in a long-term care (LTC) facility. The second type of finding was a set of six categories of dementia care expectations that were inducted during the analysis of the study group’s narratives. Throughout the entire social process, expectations of dementia care emerge in the form of caregiver expectations of the LTC facility. The expectations of dementia care are: (1) all-round patient care, (2) pleasant surroundings, (3) a competent staff, (4) a caring staff, (5) prompt communication of developments related to the loved one’s condition or care, and (6) responsiveness to the family’s questions and concerns. These specific care expectations that family members revealed in their narratives emerged within and throughout the context of the social process, “Coming to Terms.”

The narrative responses demonstrated that family members made transitions through five stages and exhibited specific behavioral phenomena while formulating their expectations of dementia care. As they transitioned to the caregiver role (Stage 1), they saw losses. Eventually they took on caregiver roles (Stage 2) to “fill the gaps”. In time, they began to relinquish caregiver roles (Stage 3) after “recognizing their limits” and “acknowledging the need for long-term care”. Accepting the relinquishing of care provided family members with a basis upon which to draw expectations of how others would provide care. Over time, as they selected and evaluated the LTC facility (Stage 4) and strategized what they would do if expectations were not met, they became clearer about the permanence of the LTC placement. Finally (Stage 5), the family members accept their loved ones’ LTC status. Based on their acceptance of that status and their acceptance of care the LTC facility provided, the family members justified their decisions

to place their loved ones in the LTC facility. Thus, ultimately, the family members found themselves “Coming to Terms” with their decision.

## **CHAPTER FIVE**

### **DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS**

#### **Introduction**

This chapter will discuss the findings of the study in the context of the contributions they make to knowledge that supports the discipline of nursing and to propose potential outcomes resulting from the translation of these findings into practice with dementia residents and their families. The aims of this study were to: (1) elicit the subjective perspectives of family members about what constitutes quality long-term care (LTC) for loved ones with dementia, and (2) develop a grounded theory of shared meanings of quality dementia care that reflects the basic social process by which family members formulate expectations of care delivered in LTC settings.

The findings, reveal a basic social process called, “Coming to Terms.” Grounded in the narrative data collected during dialogues with family members, “Coming to Terms” emerged from stories they told about their personal journeys during which they made various decisions, acted to meet the needs of their loved ones, and formulated expectations of long-term dementia care that were based on their lived experiences as caregivers. Specifically, throughout the five-stage process that emerged as “Coming to Terms” (Figure 4.1), family members simultaneously anticipated, performed, reflected upon, and evaluated their caregiving activities in the context of their loved ones’ ever-changing needs and their own ability to meet those needs. Behavioral phenomena that accompanied the family members’ perceptions and interpretations of their own limits as caregivers, allowed the investigator to appreciate and bring to the fore the conscious and sometimes unconscious expectations of dementia care that study participants were forming. As care demands of their loved ones escalated and their own caregiving abilities diminished, family members identified the care they wanted others to provide as they deliberated about when, how, and where they would place their loved ones in LTC.



Family caregivers experienced the realities of dementia care during each stage and transition in the process of “Coming to Terms.” “Coming to Terms” revealed how family members processed their realities and turned those realities into expectations of how they wanted others to care for their loved ones. The six expectations of long-term dementia care that the study group formulated are: (1) fulfill their loved ones’ basic needs, (2) provide pleasant surroundings, (3) ensure a competent staff, (4) ensure a caring staff, (5) facilitate communication, and (6) practice timely institutional responsiveness. Family members used the expectations they formulated to examine and select a LTC placement they believed would meet the needs of their loved ones.

“Coming to Terms” illustrates the five-stage social process that family members move through when dementia affects a loved one, and how, during those stages and transitions, the list of care expectations is formulated. Thus, the family members’ expectations of long-term dementia care do not suddenly emerge full-flower. Rather, they germinate over time and represent the synthesis of the family members’ personal experiences of caring for the loved ones at home, their failure to fully satisfy the loved ones’ basic needs, their mixed emotions attendant to relinquishing their loved ones’ care, and, ultimately, their acceptance that the loved ones’ conditions justify and, indeed, required long-term dementia care.

The extant literature provides only limited insight into family members’ expectations of long-term dementia care and the processes through which they are developed. Accordingly, the findings of this study contribute to the understanding of what the consumers of long-term dementia care want, and how and why they feel as they do. A discussion of this study’s findings is presented in the following sections.

### Discussion of the Historical Significance of This Study

It has been over twenty years since the Nursing Home Reform Act (1986) was passed in response to the National Institute of Medicine’s (IOM) study of the LTC industry. That study was commissioned in response to the public’s outcry that individuals residing in nursing homes were not receiving the quality care they deserved. Although the

Nursing Home Reform Act and subsequent legislation under the Medicare and Medicaid programs were designed to correct those ills and stimulate sweeping changes in the LTC industry, public criticism of nursing home care continues unabated. Complaints about poor quality care continue to be filed with nursing home administrators, state and national leaders, and attorneys who make it their business to assist families seeking damages for abuse, neglect, and wrongful death of their loved ones. It was against this background that the significance of this study was founded. It is important and timely to discover what consumers themselves expect of long-term dementia care and translate those findings to the development and revision of national and institutional policies, procedures, and benchmarks.

The timeliness of this study and the importance of translating its findings into practice are based on US population demographics that predict large increases in the number of elderly who will experience dementia as baby-boomers age. Correspondingly, more family members will find themselves seeking out quality long-term dementia care for their loved ones and bearing the responsibility of speaking out for loved ones who cannot speak for themselves. Although a number of studies have looked at expectations of long-term care from the viewpoints of both residents and family members (Bliesmer & Earles, 1993; Bowers, 1988; Chou et al., 2002; Grando et al., 2002; Strang et al., 2006; Train et al., Wilson, 1989), none have concentrated solely upon the long-term care expectations of family members whose loved ones suffer from dementia.

There remains a paucity of studies that explain in detail what family members go through from the point they learn their loved ones suffer from dementia to the loved ones' placement in LTC facilities. This study begins to fill the gap by adding to and expanding upon previous studies that address these issues. It is among the first to delineate the processes involved in family members' transitions as caregivers, including the behavioral phenomena they experience and the expectations of long-term dementia care they formulate.

## The Significance of the Findings in Relation to Other Studies

### *Expectations of Care from the Perspective of the Consumer (Patient)*

Given the relative paucity of studies related to consumers' expectations of LTC and long-term dementia care, placing this study's findings in the larger context of health care expectations that consumers hold is somewhat challenging. Even though dementia patients are distinguishable from the general patient population due to their cognitive deficits and inability to speak for themselves, attention to expectations of care they have the right to expect must be amplified through the voices of their family members. While the case can be made that expectations of family members may differ somewhat from those of individuals with dementia, the fact remains that family members must be viewed as spokespersons and advocates for those whose abilities to express themselves are compromised. Despite these assumed differences, several studies reported in the literature present findings that make a case for relying on expectations of consumers to plot the course for health care. "Coming to Terms" serves such a purpose for long-term dementia care.

Oermann and Templin (2000) conducted an exploratory study to examine the attributes of quality health care from the perspective of the general consumer. The study linked expectations of care to patient satisfaction, using a model developed by Kravitz (1996) in his meta-analysis of patient expectations of medical care. Kravitz showed that individuals' expectations of care are formed before their encounters with medical care and encompass both general expectations of care as well as specific expectations for a particular event (Kravitz, 1996; Oermann & Templin, 2000). Notwithstanding the demographic and role differences between the participants in these earlier studies and those in the present study, common findings support the conclusion that consumers' expectations of care emerge over time rather than as a knee-jerk response to an immediate crisis or need.

Three other studies looked at patient expectations of care within LTC settings (Bliesmer & Earles, 1993; Chou et al., 2002; Donabedian, 1988). Chou et al. conducted a cross-sectional survey study addressing the components of resident satisfaction in

residential aged care. They recruited over 1000 subjects living in a variety of nursing homes across a large geographic region and assessed their satisfaction using a self-reported resident satisfaction questionnaire. Six dimensions that the twenty-four item questionnaire measured were the: (1) room, (2) home, (3) social interaction, (4) meal service, (5) staff care, and (6) resident involvement. Chou and associates statistically developed a larger construct of quality care expectations by merging data sets and concluded that the residents' perceptions of the degree of quality care and staff care they received played a central role in determining all other aspects of resident satisfaction.

Chou et al.'s (2002) study findings provide a basis for the translation of this study's findings into practice when the goal of delivering care that meets quality expectations of families and residents is considered a priority. The findings of Chou's group also affirm the findings of this study in that agreement between LTC staff, families, and residents about what those expectations of quality care actually are can reduce dissatisfaction and increase confidence that consumer voices are heard and used to direct care. Using this study's findings in practice implies that families, prospective residents, and staff sit together and share expectations and realities, negotiate for acceptable expectancies, and make plans to regularly evaluate how everything is going. The stages and transitions displayed in "Coming to Terms" include the behavioral phenomena experienced by the study group so that LTC facilities can gain greater insights into the intentions of family members. First and foremost, family members want the best for their loved ones because they no longer could provide care at the levels they once did or hoped to do themselves. None of the study participants criticized the LTC facilities or threatened litigation to force the delivery of quality care. Their stories brought to the fore the disappointing reality that family members and facilities' representatives rarely discuss care expectations. Rather, family members identified the care they believed was needed by their loved ones and used their expectations to gather, screen, and select the facility where their loved ones would be or already had been admitted.

The findings of Chou et al. (2002) and this study also demonstrate the central importance care expectations have in determining quality and satisfaction. “Coming to Terms”, revealed in the current study’s findings, adds a dimension that supports how family members process realities that conflict with expectations, whether those expectations are spoken, unspoken, conscious or unconscious. We must improve practice by eliciting expectations of care from family members and residents and engaging in dialogue about how expectations can be met, adjusted, and resolved. While both the Chou et al. study and this study have limitations, the findings can be used to advance practice in LTC, especially with the dementia population and their families. Expectations found in both study’s findings regarding a caring and competent staff provide greater evidentiary support for efforts of LTC facilities to improve staff competence.

Bliesmer and Earles (1993) used one of the three categories (structure, process, and outcomes) from Donabedian’s (1988) work, in an outcomes approach to study what LTC residents viewed as indicators of quality care. The researchers aimed to discover if nursing home residents and nursing home nursing staff had similar views about seventeen quality indicators. The investigators hypothesized that “there should be congruence between resident and staff perceptions of the importance of indicators of quality in LTC settings” (Bliesmer & Earle, 1993, p. 31). However, minimal to moderate congruence of perceptions was found. Noteworthy, however, was the finding that prompt attention to needs and problem resolution were the two indicators of quality that were most important to the residents. This finding is consistent with findings from the current study whereby the expectations of quality dementia care revealed by the participants in the context of “Coming to Terms” communication and responsiveness.

Grando et al. (2001) conducted a descriptive study to discover why residents with light care needs entered and remained in LTC facilities. One aim of the study was to learn about care expectations these residents had. Enrolled were 20 residents who, by staff’s assessment, required little daily assistance and had no clinical conditions that needed monitoring or skilled care. Enrollment was limited however, to residents who were cognitively intact. It is unfortunate that residents with dementia and their personal

representatives were not eligible to participate, because once again the voices of the largest percentage of nursing home residents were silenced. Just as Kravitz (1993) found in his meta-analysis, studies of care expectations must include individuals who represent the full spectrum of users of services to avoid skewing study results and biasing interpretations of findings. The findings of this study, “Coming to Terms” revealed that expectations of care evolve over time throughout the stages and were meaningfully consistent among the study group even though the participants varied on demographic characteristics, prior knowledge and experiences with LTC, and time involved with caregiving.

Despite the need for more research in the area of quality dementia care, relatively few studies have been conducted with dementia patients themselves. This can be explained, in part, by concerns about whether patients with dementia can accurately and consistently describe and elucidate their expectations of care when the central core of dementia is a lack of cognitive ability and can give informed consent. This concern brings to light the significance of including family members who know the patients well in studies so their voices are heard.

The Mini-Mental Status Examination (MMSE), a dementia screening tool (Folstein et al., 1975), has been used to validate the inability of many dementia patients to engage in research that involves discussions of their perceptions and appraisals of the environments in which they live and the care they receive. Nonetheless, Iwasiw et al. (1996, 2003) conducted two studies of residents diagnosed with dementia to describe their expectations of care. They employed samples of patients with MMSE scores of 24 or higher on the grounds that cognitive abilities would permit those individuals to describe their LTC experiences. Iwasiw and associates found that residents who had been actively involved in the decision to move to a LTC facility reported positive reactions to the move and easier transitions to their new environments. While there may be limited opportunities for people with dementia to participate in research studies, there is an urgent need to have their proxies delivered by family members who love them.

Findings of the Iwasiw et al. studies have limitations based on the fact that clinicians do not agree that an MMSE score greater than 24 conclusively indicates a diagnosis of dementia. Therefore, the individuals Iwasiw et al. studied may have been in LTC facilities for reasons other than their cognitive status. The limitations inherent in the Iwasiw et al. studies underline the importance of interviewing those who are closest to them, the family members.

*Expectations of Care from the Perspective of the Patient and Caregiver (Family Member)*

Train et al. (2005) conducted a qualitative study that examined the LTC experiences of residents with dementia (MMSE < 24), their relatives and staff. The investigators determined whether the resident participants understood informed consent and the study's interview questions by making judgments based on the types of responses they heard to questions they asked. Train et al. found that even though the family members who were former caregivers were no longer responsible for the day-to-day care of the resident, some still exhibited an increased level of psychological distress. Similar disclosures were found in "Coming to Terms" when family members talked about how hard it was to reach the decision about LTC and how guilt and worry remained parts of their daily lives after the LTC admission.

Train's (2005) team also found that "all groups [families, residents, staff] talked about improving the lines of communication" (p. 119), just as the family members in the present study expressed communication as one of their six expectations of quality dementia care. That is, the study group expected open lines of communication between themselves and the LTC facility staff as well as prompt communication related to their loved ones' condition and care. This study's findings affirm the importance communication has to family members when loved ones are placed in LTC facilities. The findings add emphasis to the expectation of improving lines of communication among family and staff as found in the Train et al. study, and further explicates what and how often family members want to be informed.

Expectations about communications and remaining informed about their loved ones' conditions were consistent in "Coming to Terms." The literature reveals that these expectations of health care organizations are not limited to LTC. For example, Auerbach et al. (2005) reported similar findings from an interview study with forty family representatives of patients who were admitted to a trauma surgical ICU. Data from study participants were collected at admission to and discharge from the unit using interviews and tools. Analysis of all data revealed that the most significant aspect of care from the family members' perspective was to receive "clear, understandable, and honest information about the patient's condition" (Auerbach, et al., 2005, p. 202). It seems clear from the literature and this study's findings that communication and information are standard expectations when loved ones are separated for reasons of illness, trauma, and LTC. Communication may be an expectation common to family members of patients of all types.

Riemenschneider and Raub's (2003) editorial about expectations of quality care in LTC settings stated that "today's patients and their families expect providers to demonstrate high levels of performance," noting that "the perception of the quality experience that people encounter in their daily lives will, in turn, define the level of quality they expect from LTC providers" (p. 79). "Coming to Terms" demonstrates the validity of such observations as they pertain to family members of patients diagnosed with dementia. This study's findings confirm that family members' expectations of dementia care are very much the product of their personal experiences of dementia care prior to their loved ones' admissions to LTC facilities and the expectations continue to be formulated and refined following the patient's admission. Efforts to work with families must not end following admission. Working together to understand care needs and align them with expectations and evaluations of outcomes remains critically important throughout a resident's lifetime.

Another parallel between the findings of Riemenschneider and Raub's (2003) study and this study is the revelation that people formulate expectations of quality care before, during, and after an encounter or a need presents itself. Family members in the



present study used their own experiences as caregivers and their anticipatory thinking about who would do the care when they no longer could to process expectations they could articulate. Implications of these findings suggest that it is important to query those who seek LTC about their quality care expectations before, during, and after their needs for such services emerge. Not only will this strategy expose expectations, but it begins the pattern of communications that addresses expressed needs to be informed on a regular basis and receive timely responses to questions posed. This study aimed to elicit expectations from family members and its findings contribute to advancing knowledge about improving communications between family members and LTC facilities that care for residents with dementia.

#### *Expectations of Care from the Perspective of the Caregiver (Family Member)*

Levy-Storms and Miller-Martinez (2005) conducted a study that examined the relationships between caregiver involvement and satisfaction with institutional care during the first year of residency. They enrolled 555 caregivers defined as the “primary caregivers” for persons with dementia residing in LTC facilities and surveyed the caregivers at the time of admission and one year later. They found that the more involved the caregivers were up to and at the time of admission, the less satisfied they were with institutional care at admission. When surveyed one year after admission the caregiver sample had become more dissatisfied with care than they were at the time of admission. The researchers concluded that pre-admission primary caregivers may be less satisfied than others because they had seen, first hand while caregiving, the problems they were no longer able to manage but fully expected the LTC facility to handle. A second explanation offered by the researchers addressed the issue that once the loved one had been admitted to the LTC facility, family caregivers were not included in any meaningful caregiver role (Levy-Storms & Miller-Martinez, 2005).

The goal of this dissertation was not to replicate the Levy-Storms & Miller-Martinez (2005) study; however, its findings do support the proposition that some family members wish to retain a close connection with their loved ones’ care, at least to the

extent that they want to receive frequent communications about their loved one's condition and they want the institution to be responsive to their questions and concerns. The findings of the Levy-Storms & Miller-Martinez study and of this dissertation support the need to conduct further research comparing family members' expectations of dementia care at admission, after one year, and periodically thereafter. The span of time over which participants in the "Coming to Terms" study formulated their expectations ranged from a couple of months to several years. The concepts and behaviors of the "Coming to Terms" model provide information about the focus and length of research programs that study expectations of quality care.

Family members started to learn more about dementia as they cared for their loved ones at home in the present study. Their narratives demonstrated that when it came to selecting and evaluating LTC facilities family members wanted a knowledgeable and competent staff in addition to the communication issues addressed earlier. Their narratives also revealed that many caregivers experienced conflict about making the decision to place their loved ones in LTC facilities. Most tried to find justification for their decisions and vacillated back and forth between keeping the loved ones at home and placing them in LTC. Braithwaite and McGown's (1993) study explored the capacity of emotionally burdened caregivers to learn about stroke. Their findings suggest that uncontrollable emotions in family caregivers interfered with communications with professional providers and the ability to learn new things. The Braithwaite & McGown (1993) study and this dissertation underscore the need for LTC facilities to recognize that the loved ones' family members may be stressed and fragile for months and years after their family member's admission to LTC. The emotional and behavioral phenomena revealed throughout "Coming to Terms" speak volumes about the states many caregivers are in when they make LTC decisions. LTC facilities could ease the family members' emotional burden by forming a partnership with them in developing and executing the plans of care for their loved ones. Further research should be conducted to determine the benefits, drawbacks, and outcomes of such a partnership.

Wilson (1989) used a grounded theory approach and a sample of 20 family caregivers to explore and describe the process of home-based family caregiving for loved ones with dementia. Wilson observed the profound psychological downhill course that was experienced by the caregivers as care needs of their loved ones with dementia rose. The study revealed that family members were constantly thinking about and dealing with the negative choices associated with caring for someone with dementia at home. One extreme example of a negative choice was the question whether to relinquish the caregiving role to an institution or to remain the caregiver despite ever-increasing care demands.

Wilson (1989) reported the emergence of a basic social process grounded in the stories of her participants which she labeled as “Surviving on the Brink” and it is a three-stage process that reveals how family caregivers in her study attempted to cope with making tough choices. The stages were: (1) taking it on, (2) going through it, and (3) turning it over (Wilson, 1989). It was during this third stage that caregivers in Wilson’s study made the decision to relinquish care to a third party, usually a LTC facility. The findings of the present study expand the stages in a caregiver transition process beyond what Wilson described. Through its five stage transition model (accompanied by behavioral phenomena and expectations of care), “Coming to Terms” describes family members’ trajectories beginning at the point where changes observed in a loved one precipitate actions on their behalf all the way through to placement of the loved one in a LTC facility. Thick and rich descriptions of this study group’s experiences have enabled the expansion, explication, and illustration of the social processes involved. Nevertheless, further research is needed to gain additional insight into “Coming to Terms” so that appropriate interventions can be developed.

Wright et al. (1999) published a longitudinal descriptive three-group comparison study that examined emotional and physical health of spouse caregivers of persons with dementia and stroke. The team enrolled 14 spouses who were caring for loved ones with dementia, 14 spouses who were caring for loved ones who had had a stroke, and a control group of 14 individuals who did not have any caregiving responsibilities. Face-to-face

interviews were conducted upon enrollment into the study and were repeated at six months and one year. Wright's team hypothesized that because of the progressive deterioration of patients with dementia caregivers would experience more adverse health events than those caring for persons who had suffered a stroke. Findings supported their hypothesis when data showed that caregivers of persons with dementia had higher levels of depression than stroke caregivers.

The findings of the present study differ from those of Wright et al. (1999) in that study participants did not report experiencing depression. Although family members in the study group expressed feeling guilty about placing their loved ones in LTC facilities, they also expressed relief and feelings of justification related to knowing that they no longer faced having to do something that was quickly growing beyond their reach and ability. The fact that the "Coming to Terms" study group did not report feeling depressed in no way minimizes the significance of Wright et al.'s important recommendation that interventions with caregivers be directed carefully and appropriately. The present study contributes a broadened awareness of the range of emotional and behavioral phenomena that family members may experience as they move through various stages and transitions in the caregiving trajectory. Indeed, one additional consideration, facilitated by the Wright group and this study, is that attention should be paid to the type of illness or disability the loved one has so that information about it becomes part of processes like "Coming to Terms". Knowing more about what lies ahead helps caregivers make necessary decisions, as illustrated in the stories of this study group. The "Coming to Terms" model can guide the development of more effective educational and support programs that are tailored to the particular stages in which the family members find themselves.

Strang et al. (2006) conducted a qualitative exploratory study to describe the experiences of family members waiting for nursing homes placement of their loved ones with dementia. Participants (n=41) were interviewed when their loved one's name was placed on a waitlist at a LTC facility, at three-month intervals until the time of admission, and finally, shortly after the loved one's admission to a facility. Findings from the study

also revealed a caregiver transition process. This process involved four themes identified as: (1) crisis as an initiator, i.e., a sudden awareness of the loved one's mental and physical deterioration and a need for long-term care, (2) a need for synchronicity, i.e., caregiver readiness for placement and the availability of a bed in a LTC facility, (3) control, i.e., a search for help and guidance to maintain control, and (4) reciprocity, i.e., the [patient] cared for me; therefore, I need to care for [them] (Strang et al., 2006).

The narratives in "Coming to Terms" echo some of the findings of Strang et al. (2006). However, the study's findings expand knowledge of caregiver experiences and transitions in two respects: (1) it more fully describes the social process through which family members go from the point of recognizing something was wrong with their loved one through the decision to seek LTC, and (2) it reveals the family members' expectations of long-term dementia care and illuminates how they are developed and refined in each stage of the transition process. "Coming to Terms" adds knowledge about dementia care expectations as well as the subjective perspectives of caregiving experiences and LTC decision-making. The transitions and behavioral phenomena the study group revealed bring to the fore many opportunities to build better understandings between residents, family members, caregivers, and LTC facilities.

#### Transition Model Comparison: Transition Cycle of Change and "Coming to Terms"

The term, "transition," is a passage from one form, state, style, or place to another (American Heritage Dictionary, 2000). Transition theories explain bereavement, families in crisis, and depression (Hopson & Adams, 1976; Kubler-Ross, 1972; Lewin as cited in Likert 1947). Several researchers and theorists have used transition frameworks to explain phenomena associated with making decision about LTC placement for loved ones (Stull et al., 1997; Duncan & Morgan, 1994; Wilson, 1997). Other authors have more specifically described caregiver transitions experienced when an elderly relative with dementia is admitted to a LTC facility (Cohen et al., 1993; Colerick & George, 1986; Dellesega & Mastrian, 1995; Grando et al., 2002; Hagan, 2001; Johnson et al., 1994; Lieberman & Kramer, 1991).

Schumacher and Meleis (1994) describe the universal properties of transition as processes, directions, and changes in fundamental life patterns. They also concluded that transitions at the individual and family level consist of changes in identities, roles, relationships, abilities, and patterns of behavior. Participants in the present study certainly experienced all of these factors as they moved through the five stages in “Coming to Terms.”

Expanding on earlier theoretical works put forth by the team, Meleis et al. (2000) conducted a conceptual analysis on the “transition framework” used in nursing. They noted that “transitions” are both a result of and a result in changes in lives, health, relationships and environments. They further described the concept of transition as a middle-range theory. Missing from the work of Schumacher and Meleis (1994) and that of Meleis, et al. are identifications and descriptions of specific stages in the transition process model; leaving some to doubt the claim that the concept of transition is middle-range theory.

Others outside the discipline of nursing have been developing and expanding transition models and theories that have relevance to nursing’s metaparadigm. The one who was most influential in guiding the questions and design of this research study is Nicholson (1990). Nicholson (1990) has suggested that a change due to a life event is not linear but circular. As discussed in Chapter 2, Nicholson’s “Transition Cycle of Change” model is comprised of the following four stages: (1) preparation, (2) encounter, (3) adjustment, and (4) stabilization (Nicholson, 1990). (See Figure 1.1, p. 11) Nicholson purports that during the preparation stage, the individual achieves a state of readiness by being aware of his or her own feelings and is positively motivated to develop “clear and realistic expectations” (p. 88). In the encounter stage, no matter how well prepared the individual is, new and unexpected experiences may occur. Individuals cope with the unexpected by trying to make sense of it. Having made sense of the unexpected, the individual makes personal changes, develops a new role, and provides for relationship building in the third stage called adjustment. Finally, in the fourth stage called stabilization, the individual establishes and sustains trust, becomes confident with his or

her commitment and effectiveness with tasks and people, and gains the momentum to move into the preparation stage of yet another transition cycle.

Nicholson's (1990) "Transition Cycle of Change" was used as a sensitizing framework for this study. However, similarities to and differences from Nicholson's model emerged from the present study. For example, one could superimpose the "Coming to Terms" transition model over Nicholson's "Transition Cycle of Change" and draw parallels from one to the other. The "Coming to Terms" Stage I – Transitioning to the Caregiver Role, could be viewed as the equivalent of Nicholson's preparation phase. On the other hand, the "Coming to Terms" model diverges significantly from Nicholson's cyclic model where "[e]ven the most stabilized conditions contain the possibility for future change, and, therefore embody varying states of readiness for the onset of a new cycle. For this reason, Stage I is also Stage V" (Nicholson, 1990, p. 87). In contrast, the "Coming to Terms" transition model falls short of having a stabilization stage, most appropriately explained by the fact that the dementia illness trajectory does not stop when the loved one is placed in a LTC facility. The trajectory stops at death. The present study enrolled only family members whose loved ones with dementia were still living; therefore, further study is recommended and should include family members whose loved ones have died in order to address the validity of this investigator's conclusion. Perhaps "Coming to Terms" has no stabilization-type stage as found in Nicholson's (1990) model because there is no end to the constant adjustments family members make to cope with the progressive deterioration of their loved ones with dementia. Further research is needed to explore whether this is the case or whether an expanded "Coming to Terms" transition model might better illustrate and explain the full range of experiences of family members.

#### Significance of the Findings for Nursing

Findings of this study have significance for the practice of nursing as they provide new insights into the social process that forms the context for the formulation of expectations of dementia care by family members over time. By understanding that

family members have developed their expectations of care through their own experiences of caring for their loved ones, that the family members are, themselves, in a fragile and vulnerable state, and that family members are often trying to justify their decisions to move their loved ones to LTC, nursing personnel at LTC facilities can tailor intake procedures to tap into the family members' acquired knowledge and, at the same time, better address the family members' personal anxieties and concerns. For example, nursing personnel can make sure family members are more actively involved in establishing the plans of care for their loved ones and discuss with family members exactly how and when they wish to be informed of developments concerning their loved ones' conditions. The benefits of such an approach would be threefold: First, by learning how family members cared for their loved ones at home and what problems they experienced, nursing personnel can demonstrate a sincere appreciation of the unique insights family members have about their loved ones' care needs. Second, nursing personnel are, indeed, likely to derive information about the loved ones that can help them take better care of their patients. Third, if nursing staff recognize and actively demonstrate the belief that family members continue to play an important, albeit shared, role in their loved ones' care at the LTC facility, family members may be better able to accept their loved ones' long-term care status and validate the decision they have made to seek such care.

The grounded theory "Coming to Terms" gives nursing a clear illustration of how family members experience dementia caregiving, formulate expectations of dementia care, and process decisions about placing loved ones in LTC facilities. Armed with the knowledge of what family members have been and continue to be thinking and feeling, nursing administrators in LTC settings can: (1) establish effective facility-based support groups to help family members cope with the nursing home admission, (2) conduct tours of the LTC facility that incorporate information associated with the six categories of expectations, and (3) develop literature for family members that describe the transition process.



Nursing home administrators also can develop policies and procedures that integrate the family members' expectations of dementia care into the standards they use to deliver quality care and measure the outcomes of care. Finally, the findings of this study could be used by nurse educators to orient newly-hired staff and develop and promote educational programs that bring nursing staff and family members together for the good of the residents.

#### Recommendations for Future Research

The findings of this study add to the understanding of family members' expectations of long-term dementia care and how they are developed. The emergent grounded theory sheds light on the stages through which family members progress as they transition from caregivers to the persons who make the decisions to place their loved ones in LTC facilities. It also reveals how family members select and evaluate LTC facilities in relationship to their original expectations and according to those expectations that are adapted and adjusted over time. Since the sample size was small, replicating and expanding this study into a larger and denser sample group is recommended and may serve to enhance the emergent theory.

Other recommendations for future research are as follows:

- (1) Conduct a grounded theory study to elicit and describe family members' expectations of dementia care six months after the patient's admission.
- (2) Conduct a repeated measures study (quantitative, longitudinal) that compares family members' expectations of dementia care at the time of admission with their expectations of dementia care one or more years later.
- (3) Implement a two-group quantitative study that compares within and between group differences in family members' expectations of dementia care when spouses and adult children comprise the sample.
- (4) Conduct a study that employs regression analysis to identify predictors of family involvement in nursing home care.

- (5) Conduct a phenomenologic study that extends knowledge about the lived experiences of family members who care for a loved one with dementia at home.

### Limited Application of Study Findings

The findings of this dissertation study provide a new perspective and enhance understanding of the social process of “Coming to Terms” which reveals: (1) five transition stages through which family members pass as they move from providing care to their loved ones to accepting LTC placement, (2) the behavioral phenomena that accompany each transition stage, and (3) the emergence of caregiver expectations of quality dementia care.

However, as is the case with qualitative research, the sample size was small, perhaps limiting its applicability. Using the design of this study, more grounded theory studies of this special population can be conducted in different geographical regions with participants who are demographically different from this study sample. Additional studies will extend knowledge and provide more guidance to practice and research.

### Conclusions

This grounded theory study yielded a basic social process within which family members performed care for their loved ones with dementia, experienced behavioral phenomena associated with their caregiver roles, formulated expectations of quality dementia care over time, and made decisions about LTC placement. Transitional stages that emerged as dimensions of the basic social process, “Coming to Terms” illustrated the participants’ movements through the challenges they faced and what they thought, felt, and did in response to those challenges. The results of this study are consistent with some descriptions of how other populations’ of caregivers, family members, and patients formulate expectations of care, yet they extend knowledge to provide insights into how original expectations change over time along with the transitions of the caregivers and the illness or disability conditions of the patients they care for. Rich, descriptive detail

informed these results and the participants are acknowledged and appreciated. The findings have the potential to influence the development of LTC policies and procedures with the aims of improving the transition process from home-care to LTC, educating LTC facility staff, bridging gaps between expectations of family members and LTC staff, and, ultimately, fostering greater consumer satisfaction and peace of mind.

## **Appendix A**

### Informed Consent

## **Subject Consent Form**

You are being asked to participate as a subject in the research project titled, “Family Expectations of Dementia Care at Transition to the Nursing Home”, under the direction of Michael Mistic, RN, MNsc, FNP-C. Mr. Mistic is a nurse practitioner and a doctoral nursing student at UTMB’s Graduate School of Biomedical Sciences (GSBS) Doctoral Program in Nursing. His work will be supervised by Judith Drew, RN, PhD, a Professor in the School of Nursing and the GSBS.

### **PURPOSE OF THE STUDY**

The purpose of this study is to learn about the expectations you have for quality care your spouse or parent should receive while living in this long-term care facility. This study fulfills a requirement for the PhD in Nursing. As a nurse practitioner who works with patients and families in a long-term care facility, Mr. Mistic is interested in learning how and why you chose this facility for your loved one’s placement and about the expectations you have for quality care of your parent or spouse.

### **PROCEDURES**

This is an interview study. There are no interventions or experiments. During this study, Mr. Mistic will interview you at least once or twice but no more than three times about your experiences making the decision to place your loved one in a long-term care facility and your expectations of that care. The interviews will be conducted at a time and place that is convenient for you. Each interview will last approximately one hour each and will be conducted over no more than a three-day period of time counting from the time the first interview is completed. The interviews will be audio-taped and transcribed verbatim so that data from the interview can be analyzed. The audio-tapes and transcripts will be coded and all identifying information will be removed from them. Both will be kept in a locked file cabinet in the researcher’s office. Analysis of the transcripts involves searching for any commonalities among comments made by study participants.

Following the completion of the first interview, Mr. Mistic will contact you to set up a second interview if needed. Need is determined on how much information was left to talk about when the first interview was completed. Subsequent interview sessions also provide time for you and Mr. Mistic to clarify information shared at the first interview.

In addition to participating in the interview(s), you will be asked to complete a short questionnaire seeking bio-demographic information. The bio-demographic data that will be collected and used to describe the sample are: (1) age, (2) gender, (3) relationship to patient, (4) first or subsequent marriage (if spouse), (5) number of years caring for the patient at home or other location, (6) occupation, (7) number of children in the family (if child of patient), (8) type of social support used or preferred, and (9) previous experiences with LTC placement decision (self, relative, or friend). Bio-demographic data that will be collected about the loved one to be admitted will include: (1) age, (2) gender, (3) number of years diagnosed with dementia, and (4) years of school completed. This questionnaire will also be coded so that no identifying information can be associated with you. If, for any reason, you are unable to continue your participation in any interviews, they will be stopped.

### RISKS OF PARTICIPATION

The potential risks of participation in the study are a possible loss of confidentiality and fatigue due to the interview process. To protect you from a loss of confidentiality, study materials are coded and your name will never appear on any study documents. Others will only learn of your participation in this study if you tell them yourself. Study findings will be reported in the aggregate so that what you say cannot be linked to you directly. If you become fatigued during the interviews, you may ask to stop the interview at any time.

### NUMBER OF SUBJECTS PARTICIPATING AND DURATION OF PARTICIPATION

The anticipated number of subjects involved in this pilot study will be no more than 20. All will be recruited from long-term care facilities in the greater Houston-Galveston area. The length of time for your participation will consist of at least one but not more than three interview sessions. No interview session will last longer than 90 minutes. The interviews will be conducted at a place and time that is convenient for you. The frequency of the meetings will be established by the progression through the interview and the investigator's need for content clarification. This study will begin in October 2006 and will be completed by September 2007. While this study will go on for nearly a year, your participation as an individual will be completed within three months of the date you sign this consent form (if you choose to do so).

### BENEFITS TO THE SUBJECT

There are no direct benefits to you for your participation in this research project. By answering the researcher's interview questions, you may gain some insight into the expectations you have of quality care while your loved one is living in a long-term care facility.

### OTHER CHOICES (ALTERNATIVE TREATMENT)

There are no treatments in this study. You will meet with the investigator only to discuss interview questions. The alternative to participating in this study is to choose not to participate. Participation in this study is voluntary and not required.

### REIMBURSEMENT FOR EXPENSES

There will be no reimbursement of expenses because interviews will occur at the long-term care facility.

### COMPENSATION FOR RESEARCH RELATED INJURY

There are no treatments or substances given to you as part of this study's procedures. This is a study that only involves being interviewed by the researcher. The likelihood of you sustaining any type of physical injury because of your participation is extremely rare. However, if you are physically injured in any way because of your participation in this study, UTMB will provide you with the appropriate medical treatment not covered by your own insurance or health care program at no cost to you to the fullest extent permitted by Texas law. You will be responsible for paying any costs related to illnesses and medical events not associated with being in this study. No other forms of compensation are available. However, you are not waiving any of your legal rights by participating in this study.

### COSTS OF PARTICIPATION

There will be no cost to you for your participation in this study.

## USE AND DISCLOSURE OF YOUR HEALTH INFORMATION

Even though in this interview study no health information is accessed, collected, or used, you must know that all study records that identify you will be kept confidential as required by law. Federal privacy regulations provided under the Health Insurance Portability and Accountability Act (HIPPA) provide safeguards for privacy, security, and authorized access to your records. These regulations require UTMB to obtain authorization from you if it or anyone employed there attempts to use and disclose your health information. By signing this consent form, you are agreeing to participate in this study. You are not authorizing the use and disclosure of your health information related to this research study.

Except when required by law, you will not be identified by name, social security number, address, telephone number, or any other direct personal identifier in study records. This interview study about family expectations of dementia care at transition to a nursing home does not require that Mr. Mistic collect any of your health information, nor will he access any of your health records. However, you do need to know that study records will be coded without your name and be kept confidential as required by law. You will not be identified in study records. A code number will be assigned to you and only Mr. Mistic will know that number. The key to the code will be kept in a locked file in Mr. Mistic's office.

There are no sponsors for this research since it is a required project for Mr. Mistic. The study data, meaning the contents of your interview(s), will not be linked to you as an individual. Instead, the data you provide will be put together with data from all other participants and reported that way.

If you sign this form, you are giving Mr. Mistic permission to collect, use and share the data you provide during the interviews about family expectations of dementia care at transition to a nursing home. Your health information is not part of this study and you will not be asked about it nor will it be assessed. You do not need to sign this form. If you decide not to sign this form, you cannot be in the research study. Whether or not you agree to participate in the research project or give us permission to collect, use or share your interview information will not affect the care you will be given at UTMB.

Mr. Mistic will use and disclose your interview, mixed with all other interview data, to complete the research study and present themes found in all the interviews in his dissertation. Remember, Mr. Mistic does not collect or access any of your health information, therefore, your medical and health records are not relevant to this study. You may see or receive a copy of any research reports of findings from this study at its conclusion.

Your interview data (without your name) may be reviewed by members of the study team, for example, Dr. Judith Drew, for purposes of understanding common thoughts about family expectations of dementia care at transition to a nursing home.

If for any reason you want to stop your participation in this study, you can at any time. However, you need to inform Mr. Mistic at the contact numbers listed in this consent form. You need to say that you have changed your mind and do not wish to continue participating in this study. At that time and thereafter, Mr. Mistic may not collect any additional interview data from you. However, he may use the interview data that is already collected. It is important to learn everyone's experiences, not just those of persons who complete the research study. The results of this study may be published in scientific journals and presented as posters without identifying you by name.

### ADDITIONAL INFORMATION

1. An offer has been made to answer any questions that you may have about these procedures. If you have any questions before, during or after the study, or if you need to report a research related injury, you should immediately contact Mr. Michael Mistic, RN, MNSc, FNP at (713) 794-7162 or, if after normal office hours, at Pager (713) 841- 0031 or, Dr. Judith Drew at (409) 772-8227.
2. Your participation in this study is completely voluntary and you have been told that you may refuse to participate or stop your participation in this project at any time without penalty or loss of benefits and without jeopardizing your medical care at UTMB. If you decide to stop your participation in this project and revoke your authorization for the use and disclosure of your health information, UTMB may continue to use and disclose your health information in some instances. This would include any health information that was used or disclosed prior to your decision to stop participation and needed in order to maintain the integrity of the research study. If we get any information that might change your mind about participating, we will give you the information and allow you to reconsider whether or not to continue.
3. If you have any questions regarding your rights as a subject participating in this study, you may contact Dr. Wayne R. Patterson, Senior Assistant Vice President for Research, Institutional Review Board, at (409) 266-9475.

The purpose of this study, procedures to be followed, risks and benefits have been explained to you. You have been allowed to ask questions and your questions have been answered to your satisfaction. You have been told who to contact if you have additional questions. You have read this consent form and voluntarily agree to participate as a subject in this study. You are free to withdraw your consent, including your authorization for the use and disclosure of your health information, at any time. You may withdraw your consent by notifying Michael Mistic, RN, MNSc, FNP-C at (713) 794-7162 or, if after normal office hours, at Pager (713) 841- 0031 or, Dr. Judith Drew at (409) 772-8227. You will be given a copy of the consent form you have signed.

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Date

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Signature of Subject

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Signature of Witness

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Signature of Authorized Representative (*if applicable*)

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Description of Representative's Authority to Act for Subject (*if applicable*)

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Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject and/or his/her authorized representatives.

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Date

---

Signature of Person Obtaining Consent



## **Appendix B**

Bio-demographic Data sheet

**Bio-demographic Data**

Participant Code Number: \_\_\_\_\_

**Interview Data (Family Member)**

1. Age:
2. Gender:
3. Ethnicity:
4. Relationship to patient:
5. First or subsequent marriage (if spouse):
6. Number of years caring for the patient at home or other location:
7. Occupation:
8. Number of children in the family (if child of patient):
9. Type of social support used or preferred:
10. Previous experiences with LTC placement decisions (self, family, or friend):

**Spouse or Parent Data (the Resident)**

1. Age:
2. Gender:
3. Number of years diagnosed with dementia:
4. Number of years of school completed:

## **Appendix C**

### Interview Guide

## **Interview Guide**

Participant Code Number: \_\_\_\_\_

### **Transition to Long-Term Care**

Tell me what a typical day was like before your [*mom, dad, etc.*] was admitted to the LTC facility.

Tell me about your decision to place your loved one in a LTC facility.

Tell me about who was involved in the decision to place your loved one in a LTC facility.

Tell me about your impressions of the LTC facility you selected for placement.

Probe for:

- Describe decision
- Describe LTC facility selection
- Describe first impressions of the LTC facility selected

### **Care Expectations**

Tell me what a typical day is like since your [*mom, dad, etc.*] has been admitted to this LTC facility.

Tell me about the care you expect your loved one to have while they are living here.

If it were perfect, tell me what would a typical day look like?

Tell me about some of the ideas you have about who should be giving the care you want for your loved one.

Tell me about the kinds of things you will do or say if your expectations are not met.

Tell me about your most favorite program at this facility.

Tell me about your least favorite program at this facility.

Probe for:

- Staff communication
- Frequency of communication

Tell me how it has been going for [*resident's name*].

Tell me how it is going for you.

What else should I have asked you? Is there anything else you would like to say?

## **Appendix D**

### Recruitment Letter

Recruitment Letter of Solicitation for Participation in Study:

**Family Expectations of Dementia Care at Transition to the Nursing Home**

Dear Family Member,

If you think you might be interested in learning more about a research study that is being conducted to describe the family expectations of dementia care at transition to the nursing home, please read on.

My name is Michael Mistic, a family nurse practitioner, and a doctoral student in nursing at UTMB. I am conducting an investigational study under the supervision of Dr. Judith Drew, a professor at the UTMB School of Nursing. Participation in the study is strictly voluntary. All information about participants will be confidential and findings will not review your identity but will serve only to guide future research. I expect to present this study as my dissertation which will qualify me to graduate with a doctorate in philosophy in nursing research.

The Institutional Review Board (IRB) at UTMB has approved this study. Their guidelines for the protection of human subjects will be followed at all times.

If you are willing to participate, please e-mail me at [mlmistic@utmb.edu](mailto:mlmistic@utmb.edu) and I will get back with you as soon as possible. If you would rather leave a message at (713) 794-7162, please feel free to do so and I will return your call as soon as possible.

Sincerely,

Michael Mistic, RN, MNsc, FNP  
UTMB Doctoral Student, Nursing  
Principle Investigator

## **Appendix E**

### Recruitment Flyer

Recruitment Flyer of Solicitation for Participation in Study:

**Persons interested in participating in a study which describes:**

**Family Expectations of Dementia Care**

An investigator is seeking voluntary adult participants (ages 18 and older) who identify them as a spouse or family member of an individual who is diagnosed with dementia and have just been admitted to a nursing home, to learn and understand family expectations of care when admitted to a nursing home. This study will permit the investigator to gather information via face-to-face taped interviews that will ultimately be used to construct and implement interventions that will contribute to policy and culture changes in the LTC industry that serves persons with dementia.

For more information or to volunteer, please call:

Michael Mistic at (713) 794-7162

or

Contact via e-mail to [mlmistri@utmb.edu](mailto:mlmistri@utmb.edu).

Thank you.



## **Appendix F**

### Code Book I

### Code Book I (Code Statements)

1.	Care (now) by family member at home
2.	Relationship of caregiver to resident
3.	Reasons caregiver is in caregiver role
4.	Event that precipitated a caregiver coming forward
5.	Reason a nursing home was considered or recommended
6.	Family member's reactions to need for a nursing home
7.	Reasons caregivers give up the caregiver role
8.	What making the nursing home decision was like
9.	Who else was involved in decision besides the caregiver
10.	What is expected from the nursing home
11.	How family member(s) feel or felt about nursing home decision
12.	How final decision was reached and who made final decision
13.	Family member impressions of nursing home following admission
14.	Family member's issues with the nursing home
15.	Criteria family member(s) use to select a nursing home
16.	How family members acquire knowledge of dementia
17.	What family member(s) say they know about dementia and people with dementia
18.	What resident able to do before going into nursing home
19.	What assistance resident needed at home before going into nursing home
20.	Reasons why family member does not want to consider nursing home
21.	Family member perception of what happens in a nursing home
22.	How family member will handle concerns if expectations are not being met
23.	What resident was doing in hospital before going into nursing home
24.	Resident has had previous experience with nursing homes
25.	Family member has had previous experience with nursing homes
26.	Family members expectations of who should be providing care when resident is in the nursing home
27.	What is expected about communication with family members
28.	When should communication occur between nursing staff and family members
29.	When should communication occur between medical staff and family members
30.	Types of activities for residents
31.	Family members perception of what resident remembers to do
32.	Family members impressions of nursing home prior to admission
33.	Who should be providing care family member wants resident to have
34.	Resident's perception of a nursing home as stated by family member
35.	Family member's expectations of nursing home prior to admission
36.	Who made decision to place resident in the nursing home
37.	How caregiver knew that resident was not able to care for self
38.	Community assistance before going into nursing home
39.	Family assistance before going into nursing home
40.	Effects of decision on family member after resident place in nursing home
41.	Reasons why other family members wanted caregiver to make decision
42.	Types of activities family members provide for resident
43.	How family members get information about resident

## **Appendix G**

Code Book II (A)

### Code Book II (A) (Collapsing Preliminary Code Statements)

<b>Resident's Life Prior to Decision for Nursing Home Placement</b>	
<b>Code Statements: 4, 5, 18, 19, 23, 24, 31, 38</b>	
4.	Event that precipitated a caregiver coming forward
5.	Reason a nursing home was considered or recommended
18.	What resident able to do before going into nursing home
19.	What assistance resident needed at home before going into nursing home
23.	What resident was doing in hospital before going into nursing home
24.	Resident has had previous experience with nursing homes
31.	Family members perception of what resident remembers to do
38.	Community assistance before going into nursing home
<b>Family Member's Interaction with Resident Prior to Decision for Nursing Home Placement</b>	
<b>Code Statements: 1, 2, 3, 7, 39</b>	
1.	Care (now) by family member at home
2.	Relationship of caregiver to resident
3.	Reasons caregiver is in caregiver role
7.	Reasons caregivers give up the caregiver role
39.	Family assistance before going into nursing home
<b>The Decision to Place Resident in Long Term Care</b>	
<b>Code Statements: 6, 8, 9, 11, 12, 15, 16, 17, 20, 25, 36, 37, 40, 41</b>	
6.	Family member's reactions to need for a nursing home
8.	What making the nursing home decision was like
9.	Who else was involved in decision besides the caregiver
11.	How family member(s) feel or felt about nursing home decision
12.	How final decision was reached and who made final decision
15.	Criteria family member(s) use to select a nursing home
16.	How family members acquire knowledge of dementia
17.	What family member(s) say they know about dementia and people with dementia
20.	Reasons why family member does not want to consider nursing home
25.	Family member has had previous experience with nursing homes
36.	Who made decision to place resident in the nursing home
37.	How caregiver knew that resident was not able to care for self
40.	Effects of decision on family member after resident place in nursing home
41.	Reasons why other family members wanted caregiver to make decision
<b>Expectations of Care in Long Term Care</b>	
<b>Code Statements: 10, 13, 14, 21, 22, 26, 27, 28, 29, 30, 32, 33, 34, 35, 42, 43</b>	
10.	What is expected from the nursing home
13.	Family member impressions of nursing home following admission
14.	Family member's issues with the nursing home
21.	Family member perception of what happens in a nursing home
22.	How family member will handle concerns if expectations are not being met
26.	Family members expectations of who should be providing care when resident is in the nursing home
27.	What is expected about communication with family members
28.	When should communication occur between nursing staff and family members
29.	When should communication occur between medical staff and family members
30.	Types of activities for residents
32.	Family members impressions of nursing home prior to admission
33.	Who should be providing care family member wants resident to have
34.	Resident's perception of a nursing home as stated by family member
35.	Family member's expectations of nursing home prior to admission
42.	Types of activities family members provide for resident
43.	How family members get information about resident

## **Appendix H**

Code Book II (B)

Code Book II (B)  
**Emergent Category Designation: Collapsing Preliminary Data Code Statements**  
**(Portion of Code Book II (B))**

**Expectations of Care in Long Term Care**

**Code Statements: 10, 26, 27, 28, 29, 30, 33, 35**

1	<b>Abuse (AB)</b>		
<b>AB</b>	10.14	AB(189)	I do not want [resident] to be physically abused
<b>AB</b>	10.23	AB(208-209)	I wish [resident's] clothes would never come up missing
2	<b>Activities (A)</b>		
<b>A</b>	10.54	AD(278-280)	...being able to give them some time to where they feel compelled to talk, to converse...
<b>A</b>	10.55	AD(280-281)	...to just have a little bit of enjoyment with other person's company.
<b>A</b>	10.64	AF(635-636)	I've been suggesting all these activities since he was in [playing word games, playing cards, writing letters]
<b>A</b>	10.65	AF(746-747)	The only thing that I would like to see is more physical activity for him
<b>A</b>	10.66	AF(752-754)	I would like to see him do some kind of exercise activity from the waist up
<b>A</b>	10.69	AF(795)	I'd like to see more physical activity
<b>A</b>	10.70	AF(795-796)	I'd like to see more outings
<b>A</b>	10.75	AG(438-439)	I would like to see the activity day back again
<b>A</b>	10.85	AH(493-494)	...get him to do some type of exercise
<b>A</b>	10.86	AH(519-520)	...would be to get him up...get...do some type of exercise with him and then...activity...
<b>A</b>	10.90	AH(540-541)	...they should have some...form of some therapists to come in and work with Alzheimer's patients
<b>A</b>	10.101	AI(471-472)	...we're going to go out and we're going to get a little exercise and you're going to do a little walking
<b>A</b>	10.106	AJ(191-194)	...feel that there's something he can go to...worthwhile for him because...the type of person that needs to move around...

<b>A</b>	10.119	AK(88)	I expect him to get some therapy, to get strong so I can take him home.
<b>A</b>	10.120	AK(97-98)	I want them [the nurses] to get him out of his room.
<b>A</b>	10.121	AK(98-99)	I want him to participate in therapy and activities, like bingo
<b>A</b>	10.134	AL(98)	I want him to have therapy
<b>A</b>	10.150	AN(851-852)	...if they could have pets brought in to visit with them
<b>A</b>	13.33	AM(383-384)	He's never been doing anything when I was there [visiting in nursing home]
<b>3</b>	<b>Cognition (CG)</b>		
<b>CG</b>	10.45	AD(223-224)	...to get her to think, to be able to process, to keep her mind working.
<b>CG</b>	10.53	AD(273-274)	...knowing that she does get a certain amount of interaction, she gets a certain amount of exposure time to other people
<b>CG</b>	10.62	AE(156-157)	I would like to see her interact more with the other people there.
<b>CG</b>	10.76	AG(462-463)	Maybe some interaction with the other residents
<b>CG</b>	10.115	AJ(220-221)	...providing the companionship for him
<b>CG</b>	10.116	AJ(556-557)	...to have the conversation with the family
<b>CG</b>	21.4	AC(147-148)	I don't expect a whole lot of socialization...
<b>4</b>	<b>Communication (C)</b>		
<b>C</b>	10.10	AB(170-171)	I expect the nurses or doctor to call me when there is a change in [resident's] condition
<b>C</b>	10.11	AB(172-173)	I expect the nurse or doctor to respond to my questions
<b>C</b>	10.12	AB(173-175)	I expect the staff to record information about [resident's] medical and social history
<b>C</b>	10.13	AB(187-188)	When the staff tell me they are going to do something, then I would like them to do it
<b>C</b>	10.20	AB(195-196)	I want the staff to act quickly about any concerns that I have
<b>C</b>	10.24	AB(290-291)	The unresponsiveness of the staff
<b>C</b>	10.34	AC(188-190)	... if I called late in the evening to see how things are doing, I would like for somebody to tell me
<b>C</b>	10.35	AC(197-198)	... I would hope they [staff] would be available to answer any questions I have

<b>C</b>	10.36	AC(203-204)	I would like to hear from them [staff] on a regular basis
<b>C</b>	10.117	AJ(557-560)	It's important to be...not everyday where...give them a report every day, but, at least, some of the issues that should be addressed
<b>C</b>	10.118	AJ(563-564)	...the most important is communication between the staff and the family
<b>C</b>	10.123	AK(110-111)	I want the doctors to tell me that he is probably going home soon.
<b>5</b>	<b>Complaints (CO)</b>		
<b>6</b>	<b>Dignity/Respect (D)</b>		
<b>D</b>	10.15	AB(190)	I want [resident] to be treated with dignity
<b>D</b>	10.17	AB(191-193)	I want staff to be aware of the care of a person with dementia and keep that in mind
<b>D</b>	10.31	AC(148-149)	I expect [loved one] to receive respect as a person
<b>D</b>	10.38	AC346-347)	I just don't want [loved one] to get abused or neglected
<b>D</b>	10.44	AD(209-211)	...not go too long in embarrassing situations or situations that lead to more health problems or infections or something of that nature
<b>D</b>	10.57	AD(290-291)	I think they can dialog with the patient and make them feel more comfortable in the process
<b>D</b>	10.73	AG(408-409)	...I expect her room to be clean and her not to be in tears
<b>D</b>	10.140	AM(459)	...that nobody is ugly to him
<b>D</b>	10.143	AN(591-593)	I was hoping that he just wouldn't be lost in the nursing home and just kind of set up in a chair and forgotten about
<b>7</b>	<b>Facility (F)</b>		
<b>F</b>	10.6	AB(128-129)	What impressed me the most is that the building was clean
<b>F</b>	10.22	AB(207-208)	[Resident's] room could be larger
<b>F</b>	10.39	AD(158-159)	One that is real clean to me...went in the main entrance
<b>8</b>	<b>General Care (G)</b>		
<b>G</b>	10.1	AB(73-74)	...so [loved one] could get good care



<b>G</b>	10.3	AB(80-81)	My [loved one] needed more attention that I or my brother could give
<b>G</b>	10.26	AC(132-133)	I'd like [loved one] to be well taken care of, not being ignored
<b>G</b>	10.40	AD(198-200)	I would be looking for care where I, at least, thought that number one, her general health was being monitored carefully
<b>G</b>	10.63	AE(228)	Whatever she wanted
<b>9</b>	<b>Hygiene (H)</b>		
<b>H</b>	10.5	AB(114-116)	I asked the nursing staff to make sure they cleaned [resident's] face after eating
<b>H</b>	10.8	AB(168)	I expect that [resident] is kept clean
<b>H</b>	10.9	AB(169-170)	I expect that [resident's] hair is groomed and combed each day and when it is messed up
<b>H</b>	10.19	AB(194-195)	I want [resident's] clothes to remain with [resident]
<b>H</b>	10.28	AC(141-142)	If [loved one] dirties [self]... that [loved one] gets cleaned up
<b>H</b>	10.29	AC(142-144)	If [loved one] is bedridden at that time...that [loved one] is turned, that [loved one] doesn't develop bedsores
<b>H</b>	10.42	AD(206)	Her bathing. Her basic cleanliness.
<b>H</b>	10.59	AE(147)	...kept as clean as possible
<b>H</b>	10.71	AG(404-405)	I expect her to get her bath every day
<b>H</b>	10.94	AH(666-667)	I should never come there and smell him before I got there
<b>H</b>	10.105	AJ(181)	...that he gets his hygiene
<b>H</b>	10.113	AJ(217-218)	...making sure he has his clothing or bathes
<b>H</b>	10.125	AL(80)	I want him to be clean
<b>H</b>	10.130	AL(87)	Help him with his bath

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