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Cultivating Knowing and Relationships: A Grounded Theory of Quality of Death in the Nursing Home

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Cultivating Knowing and Relationships: A Grounded Theory of Quality of Death in the Nursing Home

Abstract

ABSTRACT CULTIVATING KNOWING AND RELATIONSHIPS: A GROUNDED THEORY OF QUALITY OF DEATH IN THE NURSING HOME Rebecca L. Trotta, Author Sarah H. Kagan, Supervisor Understanding quality of death in the nursing home is mandated both by demographics and morality in an aging society. Nursing home residents are among the oldest and most physically and mentally frail members of our society. Today, approximately 40% of people die in nursing homes in the Untied States. Despite being a relatively commonplace event, death in the nursing home and the quality of it, are understood in limited terms. A recent dimensional analysis on palliative care in the nursing home poses "quality of death" as an outcome that could improve the experience of death in the nursing home for all involved. Quality of death assumes explicit acknowledgement of death as the event of interest, and embraces dying as an imperceptible time period that precedes it. This emergent mode grounded theory study applied qualitative event analysis techniques to prospectively verify and refine this emergent concept by delineating dimensions embedded in quality of death. Using observations, interviews, and document review, events in the lives of residents receiving palliative care were analyzed according to grounded theory methods. Through a focus on events surrounding residents' deaths, the Grounded Theory (GT) "Cultivating Knowing and Relationships" emerged. This GT provides a process whereby certified nursing assistants (CNAs) come to understand and know their residents. These CNAs develop personal relationships with residents to whom they are initially assigned for care. As they cultivate relationships with these most frail older people who are at the end of their lives, the CNAs create reciprocity and achieve gratification in their work. The findings of this study challenge current understanding of what constitutes quality, the meaning of palliative care, and the experience of death in the nursing home. By focusing on human interaction and emotional connections, Cultivating Knowing and Relationships has the potential to transform current approaches to care of those who die in nursing homes.

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Rebecca L. Trotta

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Cultivating Knowing and Relationships: A Grounded Theory of Quality of Death in the

Nursing Home

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Rebecca L. Trotta

ABSTRACT

CULTIVATING KNOWING AND RELATIONSHIPS: A GROUNDED THEORY OF

QUALITY OF DEATH IN THE NURSING HOME

Rebecca L. Trotta, Author

Sarah H. Kagan, Supervisor

Understanding quality of death in the nursing home is mandated both by demographics and morality in an aging society.   Nursing home residents are among the oldest and most physically and mentally frail members of our society. Today, approximately 40% of people die in nursing homes in the Untied States. Despite being a relatively commonplace event, death in the nursing home and the quality of it, are understood in limited terms. A recent dimensional analysis on palliative care in the nursing home poses "quality of death" as an outcome that could improve the experience of death in the nursing home for all involved. Quality of death assumes explicit acknowledgement of death as the event of interest, and embraces dying as an imperceptible time period that precedes it.   This emergent mode grounded theory study applied qualitative event analysis techniques to prospectively verify and refine this emergent concept by delineating dimensions embedded in quality of death. Using observations, interviews, and document review, events in the lives of residents receiving palliative care were analyzed according to grounded theory methods. Through a focus on events surrounding residents' deaths, the Grounded Theory (GT) "Cultivating Knowing and Relationships" emerged. This GT provides a process whereby certified

nursing assistants (CNAs) come to understand and know their residents. These CNAs develop personal relationships with residents to whom they are initially assigned for care.

As they cultivate relationships with these most frail older people who are at the end of their lives, the CNAs create reciprocity and achieve gratification in their work. The findings of this study challenge current understanding of what constitutes quality, the meaning of palliative care, and the experience of death in the nursing home. By focusing on human interaction and emotional connections, Cultivating Knowing and Relationships has the potential to transform current approaches to care of those who die in nursing homes.

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Beatrice Richards' Story

It is 6:30am, and Beatrice Richards is found cold and pale by Mary, the nursing assistant who cared for her almost daily for the past five years. Mary is shocked. She did not expect to walk in this morning and find Mrs. Richards dead. Mary wonders, how did this happen? She stands at the bedside with tears in her eyes as she takes a moment to compose herself before notifying the charge nurse. Mrs. Richards was 92 years old, had end-stage diabetes, and suffered many complications, including a below the knee amputation, severe heart disease, and removal of an eye. She was bed bound and could barely move her arms and legs, severely demented, incontinent, and unable to feed herself. Despite extreme physical and mental frailty, the possibility that Mrs. Richards could and would die soon was not discussed by anyone.

Prior to life as a nursing home (NH) resident, Mrs. Richards was fiercely independent and headstrong. She never imagined the last years of her life in a NH, much less dying there, her impending death barely acknowledged by those around her. No effort was made to provide symptom management or emotional support. Mrs. Richards was fortunate to have a loving and dedicated niece, Rosalie, who without any preparation for her aunt's death, felt helpless.

Morning activities on the unit now begin. As lights go on, beds are made, and residents are ushered into the dining room for breakfast, news of Mrs. Richards' death travels quickly among staff and residents. Despite fleeting expression of sympathy, the routine activities of the NH continue uninterrupted. Dr. Klein calls Rosalie from the nursing station at 8:00am with news of her aunt's death, as he simultaneously signs

medical records and clinical communications from a pile of paperwork. Rosalie is shocked, as she thinks back to the last time she saw her aunt, a few days earlier. Rosalie wonders aloud, "Was my aunt dying?"; she listens to the silence as Dr. Klein pauses, evidently not sure how to respond. Rosalie can't bring herself to ask more specific questions: "Was my aunt alone when she died? in pain? afraid?". She finally breaks the awkward silence and asks Dr. Klein if her aunt's death was expected. The doctor replies awkwardly, "Well, I guess so, you know your aunt was very sick." He then tells Rosalie to stay on the phone in order to make arrangements for prompt removal of Mrs. Richards' body.

Quality of Death in the Nursing Home

Beatrice Richards' story is emblematic of many NH deaths. Despite the fact that death was imminent for her, little if anything was done to ensure her comfort or ready her family for the death. Both staff and family were apparently unaware of the proximity of death, despite Mrs. Richards' significant illness burden and level of frailty. This story highlights, as well, the lack of communication about death and vividly illustrates the awkwardness and emotional distance surrounding death in a NH. Sadly, Beatrice Richards illuminates the experience of death in a NH. It highlights where the collective experience could have been so much better, had there been greater attention to the quality of the death experience. The purpose of this chapter is to provide a foundation for inquiry into the concept of quality of death in the NH and demonstrate the critical nature of the proposed study. It begins with a description of quality of end of life care in the NH and a critical examination of quality of dying. Next, preliminary work regarding

quality of death is presented. The chapter concludes with the purpose and aims of the proposed study, along with a brief description of its design and methods.

<center>Quality of Care at the End of Life</center>

Researchers and policy makers have made significant improvements to the quality of rehabilitative care in NHs, yet the quality of care at the end of life remains tenuous (Reynolds, Henderson, Shulman, & Hanson, 2002). The most tangible and established measure of the quality of care at the end of life in NHs is pain management. Research findings to date document pain management as poor. Teno and colleagues (2004) found that 31.8% of residents did not receive enough help with pain (Teno, et al., 2004); Reynolds and colleagues (2002) found that 19% of residents needed more treatment for pain (Reynolds, et al., 2002); and Forbes-Thompson and Gessert (2005) found that 80% of dying residents had unrelieved pain in the 24 hours prior to interview. Unrelieved pain is widespread and negatively affects NH residents' quality at the end of life for NH residents.

Quality indicators based on the resident experiences as they die in NHs, and the experiences of family members, are also poor. Residents and family members report neglectful personal care, social isolation, and indignity (Kayser-Jones, et al., 2003; Reynolds, et al., 2002). Family members report dissatisfaction with the quality of interactions with physicians (Wetle, Shield, Teno, Miller, & Welch, 2005) and insufficient information from which to make decisions about care at the end of life (Hanson, Henderson, & Menon, 2002; Reynolds, et al., 2002; Wetle, et al., 2005). This evidence, coupled with frequent reports of unrelieved pain, highlights issues of unacceptability, illegitimacy, and inequity for those dying in NHs. In summary, quality

reports to date indicate that NH residents often die alone and in pain (Forbes-Thompson & Gessert, 2005; Happ, et al., 2002; Kayser-Jones, 2002), families are unprepared, and the medical community is frequently indifferent (Kayser-Jones, 2002; Miller, Teno, & Mor, 2004).

<div align="center">Quality of Dying</div>

Quality of dying is the most popular metric to evaluate the quality of care provided to dying people. Quality of dying emerged from quality of life and is similarly structured. It acknowledges the needs and priorities of dying people as different from those who are expected to recover from illness or who remain chronically ill but stable and not at imminent risk of death (Steinhauser, Clipp, & Tulsky, 2002). The identification of dying as a life phase or situation for which a level of quality could be gauged signals the societal importance of this phenomenon. Quality of dying is generally operationalized as attention to symptoms, personal care, and relationships; and the honoring of treatment preferences, maintenance of dignity, and sense of peacefulness (Patrick, Engelberg, & Curtis, 2001; Steinhauser, et al., 2002). Although these indicators have been empirically tested and validated, quality of dying has significant limitations, particularly as it applies to those who die in NHs.

The first limitation is that the populations and settings used to establish and validate the domains of quality of dying do not adequately represent the NH population. Research has been conducted mostly in acute care (Lua, Salek, Finlay, & Lloyd-Richards, 2005; Steinhauser, et al., 2002) or hospice/palliative care settings (Byock, 2001; Lua, et al., 2005; Patrick, Curtis, Engelberg, Nielsen, & McCown, 2003). The process and goals of care in these settings differ dramatically from that of the NH. Whereas the hospital

setting is focused on highly technological and rapid interventions, the hospice/palliative care setting is singularly focused on providing comfort as people die.

In addition to the lack of representation of the NH setting in quality of dying, the patients targeted in the previously cited studies had terminal illnesses with predictable disease trajectories, such as cancer, AIDS (Patrick, et al., 2003), or singular organ failure (Steinhauser, et al., 2004). Frail older adults with multiple chronic illnesses, those most reflective of the NH population, were not included. Furthermore, those with dementia, a condition which afflicts a significant number of NH residents, were specifically excluded (Lua, et al., 2005; Steinhauser, et al., 2004). In summary, the patient samples and care settings used to establish and validate the domains of instruments assessing the quality of dying do not adequately represent the experience in the NH setting, nor the illness burden typical of NH residents.

A second limitation of this work is that the concept of quality of dying is predicated on prospective identification of dying. Determining who is actually dying, however, is extremely difficult (Teno, et al., 2004), especially in a NH. Lynn and Adamson (2003) describe the illness trajectory typical of frail NH residents as tenuous and unpredictable, unlike those with illnesses such as cancer, making it even more difficult to determine relative time to death (Lynn & Adamson, 2003). For NH residents, the label of dying is often applied only within hours or days of death, (Froggatt & Payne, 2006), leaving little opportunity to evaluate the quality of dying. Many residents are not identified as dying prospectively (Thompson & Chochinov, 2006). Reliance on the determination of dying to guide care planning and future interventions potentially inhibits NH residents from receiving care that is needed and desired.

As a third significant limitation, the domains that comprise quality of dying do not adequately capture the experience of death, the obvious outcome of dying. Theoretically, quality of dying implies that dying is the endpoint, not death. Dying, however, is an amorphous process with no tangible boundaries. Death, the concrete and definitive outcome of dying, is not explicit. This may explain why so many people involved in death in the NH, especially family members, are often dissatisfied with its quality (Hanson, Danis, & Garrett, 1997; Teno, et al., 2004). The concept quality of dying and death (QODD) aptly shifts the focus of quality to death itself (Patrick, et al., 2001). QODD relies on retrospective evaluation, eliminating the confusion surrounding identification of dying. Nevertheless, the domains of QODD still lack applicability to NH residents, because informants for this work were persons with AIDS and terminal COPD, both of whom resided in settings other than NHs (Patrick, et al., 2001). QODD, therefore, is still limited in its application to dying NH residents.

Despite efforts to improve the quality of the dying experience, researchers struggle to identify appropriate outcome measures accurately reflecting the experiences of patients and families at the end of life (Steinhauser, Clip, & Tulsky, 2002, p. 407). This is especially true for those who experience death in the NH. The exclusion of NH residents and explicit avoidance of death itself create significant disutility in the application of quality of dying. A shift to an explicit focus on death itself could advance inquiry and eliminate many shortcomings inherent in an exclusive focus on dying. An estimated 40% of people in the United States will die in a NH by the year 2040 (Keay, 1997). A focus on the quality of death in the NH could improve the quality of care received by dying residents.

Quality of Death: Preliminary Work

Quality of death emerged as a concept in a dimensional analysis (DA) on palliative care in the NH (Trotta, 2007). DA, as a qualitative method useful for articulating theoretical explanations of social and behavioral phenomena, assumes concepts are socially constructed, contextually situated, and defined from an implicit perspective (Schatzman, 1991). Rooted in grounded theory, DA generates a theoretical matrix consisting of five categories: perspective, context, conditions, processes, and consequences, or outcomes (Schatzman, 1991).   The matrix (Figure 1) suggested quality of death as the ultimate consequence of palliative care in the NH. Quality of death was not explicitly described in the data derived from published English language literature; rather, it was implied by the nature of the outcomes of palliative care described in that literature. Quality of death in a NH is a concept predicated on two premises: first, death is acknowledged and does not rely on a declaration of dying in advance of death; and second, as death approaches, personhood and identity are maintained.

The label of dying is rarely applied until death is imminent for NH residents (Trotta, 2007). This is consistent with a fractured rather than a smooth life to death trajectory. A fractured trajectory has two curves, a longer "life to dying" curve followed by a shorter "dying to death" curve. The fractured trajectory fosters identification of dying at a singular point in time, the point at which the longer curve ends and the shorter curve begins. Until dying is declared, death remains a theoretical impossibility. The focus of care, then, is on life with the assumption that it will not end.   In the fractured trajectory, quality of death is difficult to achieve, because death often occurs in advance

of any acknowledgement of dying.   A single smooth life to death trajectory, where death

is expected and remains connected to life, allows for quality of death.

Quality of death requires that, in approaching death, personhood and identity are

maintained. Maintenance of personhood and identity assumes preservation of identity

and rights to autonomy and privacy. It also assumes treatment with respect and dignity.

This is consistent with the first premise of quality of death, the acknowledgement of and

focus on death, and application of the single life to death trajectory. A loss of

personhood and identity is signaled by isolation and an emphasis on dependence and lack

of human value. This occurs in tandem with reliance on the identification of dying and

application of the fractured trajectory.

In summary, quality of death is a complex concept that emerged from a

retrospective investigation into palliative care in the NH. Quality of death exposes

important embedded assumptions about NH residents as they die. It focuses on dying as

a transitional experience and the maintenance of personhood and identity through death.

Furthermore, it provides a theoretical foundation for shifting current discourse from

dying to death in the evaluation of quality. The explanation provided here, however, is

limited in that it represents the findings of an individual study. In addition, quality of

death exists only as a concept and must be validated empirically to reveal relevance to

clinical inquiry and care of those who die in NHs.

<div align="center">Purpose of the Study</div>

This Grounded Theory study in the emergent fit mode seeks to verify the concept

of quality of death and to answer the question, "What is quality of death in the nursing

home?" Grounded Theory in the emergent fit mode (GTEF) relies on constant

comparative technique to extend, refine, and clarify an existing concept or theory (Artinian, 1986). GTEF allows for the verification of the nature and characteristics of a previously established concept in a specific context or situation. Prospective verification and refinement of quality of death in the NH are necessary to gauge its utility for future research and applicability to practice.

Community Geriatric Center (CGC) was selected as the field site for this study as it has many characteristics conducive to verification of the concept of quality of death in the NH. CGC is a 700 bed urban NH whose residents and staff represent a wide range of cultures and ethnicities. The NH also cares for a variety of residents, including those dependent on ventilators, those needing sub-acute rehabilitation, and those requiring specialty dementia care. In addition to its diversity, CGC also delivers palliative care. This aspect is critical to the proposed study, because the concept of quality of death stemmed from an exploration into the concept of palliative care in the NH.

Data about the phenomenon were collected via qualitative event analysis techniques. Theoretical sampling technique guided identification of index residents, secondary participants, and critical events for observation. In this study, critical events were broadly defined as occurrences in the process of palliative care. Index residents were those receiving palliative care at CGC. Secondary participants were those involved in events related to index residents. Secondary participants included the family members of residents and NH staff serving in both clinical and non-clinical roles. Observation of critical events allowed for analysis of interactions that occurred in and around death and the contextual factors that circumscribed them. Constant comparative methods were employed to correct assumptions and verify the concept of quality of death vis-à-vis the

participants' actual experience. Data collection continued until saturation on the major

themes related to death were reached.

CHAPTER TWO: THEORY AND LITERATURE REVIEW

Introduction

Quality of death in the nursing home (NH) is a concept currently constructed from extant literature that appears to be mediated by a myriad of contextual factors, though it lacks empiric confirmation. Most authors embed or imply the concept, using both quantitative and qualitative methods to explore related phenomena. None achieve direct analysis or description. Nonetheless, the clinical and public relevance of the concept is clear. Without prospective verification, the public and clinical relevance of quality of death in the nursing home – while appealing – remains unknown.

This chapter provides necessary theoretical information to approach the concept, quality of death in the nursing home, as well as a review of literature to frame this concept for further study. The chapter thus begins with a description of the theoretical lenses informing the proposed study. Symbolic Interactionism and Social Worlds and Arenas Theory provide a foundational perspective from which the study will be conducted. Donabedian's attributes of quality provide an explanation of the meaning of quality as it pertains to the proposed study. An evaluation and critique of the pertinent literature is organized using Donabedian's structure-process-outcome framework. This chapter concludes with a summary outlining direction for the proposed study.

Theoretical Lenses

Quality of death in the NH is a phenomenon highly influenced by human interaction and contextual events in the NH. Inquiry into quality of death requires relevant theoretical lenses allowing for inductive examination of interactions. Consequently, a three-tiered theoretical approach will be used. First, Symbolic

Interactionism (SI), a theoretical perspective focusing on the meaning of human interaction, serves as the grand overarching theory. Second, Social World and Arenas Theory (SWAT), a middle range theory based on SI, focuses on the social context where death unfolds. Third, Donabedian's attributes of quality inform inquiry by establishing the meaning of quality in this study. Next, the relevant literature is organized according to Donabedian's structure-process-outcome framework. Applying this framework illuminates the importance of evaluating quality of death in the NH as an outcome dependent on both structure and process of care.

Symbolic Interactionism

Symbolic Interactionism (SI), the guiding principle of grounded theory, provides a unique lens from which to investigate and understand the processes and outcomes of human behavior. There are three basic premises of SI. First, human beings act toward things on the basis of the meaning that things have for them. Blumer (1969) describes "things" as any person, object, idea, or concept that can enter one's mind (Blumer, 1969). The foundational element of SI is that meaning is central in its own right. Second, the meaning of things is derived from, or arises out of, the social interaction that one has with others. Meaning does not merely emanate from or arise through a "thing;" rather, it is the product of a process of social interaction. Viewing meanings as social products dependent on interaction contributes to the unique perspective of SI. Third, these meanings are handled in, and modified through, an interpretative process used by the person in dealing with the things he or she encounters (Blumer, 1969). Through this interpretative process, meanings are not merely applied, but act as vehicles that are constantly used and revised to guide subsequent human action. SI thus provides an ideal

foundation for an investigation into the symbolic nature of the human experience of quality of death in the NH. SI has limited use, however, in explaining the context of the event.

Social Worlds and Arenas Theory

Social Worlds and Arenas Theory (SWAT) is a middle range theory that melds the sociological and interpersonal aspects of SI with the structural aspects of organizational theory. SWAT acknowledges the influence of formal organizational structure, but focuses on the social worlds and interaction between them within an arena. As such, it provides a medium for examining the influence of the context in which events around death occur on the phenomenon itself. Social worlds are the mechanisms through which people organize social life (Clarke, 2005). A social world is a group with shared commitments and ideologies about how to approach daily life within the arena. In the NH, social worlds represent the intersection of residents with family, staff, and fellow residents. While social worlds represent personal intersections, the arena is determined by the broader organizational boundaries which house the social worlds (Clarke, 2005). The NH is an arena in both a concrete and virtual sense. It exerts both structural and organizational influence on the social worlds in which it encompasses. SWAT allows for inquiry into the structural and organizational influence of the NH on the quality of death for residents. As such, SWAT provides a broader theoretical foundation in which SI can be contextually situated.

Donabedian's Framework for Quality Assessment

Definition of Quality

Death, regardless of where it occurs, is literally and figuratively the ultimate human experience. It is feared by some, sought by others, and inevitable for all. While it is a profound human experience, judging its quality is equally profound and far more complex than for any other life event. Loved ones left to judge the quality of death in a NH are also left to ponder our collective humanity and the distribution of justice. Those who die in NHs are among the most vulnerable and marginalized groups in society. The death of Beatrice Richards illustrates and personalizes the social construction of death in the NH. Exploration into quality of death in the NH requires an understanding of the way in which attributes of quality circumscribe the uniqueness of the NH setting and the ways in which people die there.

Judging the quality of an experience such as death requires a frame from which it can be evaluated. The work of Avedis Donabedian, a classic quality theorist, has been widely applied to evaluate the quality of health care delivery and its outcomes over the past several decades. Donabedian (2003) proposed seven attributes of quality in health care to evaluate the magnitude of quality (Donabedian, 2003): efficacy, effectiveness, efficiency, optimality, acceptability, legitimacy, and equity. The first four attributes relate to concrete aspects of quality, while the latter three address more humanistic and ethical aspects. *Acceptability* is conformity to the wishes, desires, and expectations of patients and their families. *Legitimacy* is conformity to social preferences as expressed in ethical principles, values, norms, mores, laws, and regulations. *Equity* is conformity to a principle of justice and fairness in the distribution of health care and its benefits among members of the population. The attributes of acceptability, legitimacy, and equity have

been chosen to guide inquiry into quality of death in the NH because of their ethical

breadth and the inclusion of family and societal views and preferences.

Structure-Process-Outcome Quality Framework

       Quality is a perception predicated on meaning and highly influenced by context

and expectations. Donabedian's framework can be used as an approach to the acquisition

of information about the presence or absence of the attributes that constitute quality

(Donabedian, 1980). In this chapter, Donabedian's framework (structure- process-

outcome) guides the organization and evaluation of current literature pertinent to quality

of death. *Structure* refers to the relatively stable characteristics of the human, physical,

and financial resources of an organization. The structure has both direct and indirect

effects on both process and outcome. *Process* is the set of activities occurring between

practitioner(s) and resident(s). Judgment of the quality of the process requires an

evaluation of the way in which outcomes affect the health and welfare of individuals

engaged in the process. This complex relationship is governed by both available medical

knowledge and norms that arise from the values and ethical principles that guide human

relationships. These norms are meaningful because they contribute to valued

consequences. *Outcomes*, or consequences, refer to a change in the resident's physical,

social, and psychological status, as well as satisfaction with care (Donabedian, 1980).

Organizing the relevant literature in this way reveals both gaps in understanding and

assumptions about quality.

       While some authors explicitly describe attributes of structure, process, and/or

outcome, many do not. For those who do, the dialectic nature of this framework and its

utility in advancing an understanding of quality of death in the NH is undeniable. For

those who do not, the framework is implicit in the findings, and clearly has implications

for understanding the way in which care is delivered to NH residents as they die.

Elements of quality are also both implicit and explicit. In this chapter, application of

Donabedian's framework exposes the dependency of outcomes on both structure and

process, and highlights the need for a focused evaluation of quality of death in the NH.

Structure of the Nursing Home

The structural attributes of a health care setting broadly encompass characteristics

of the care setting, as well as characteristics of the providers of care in that setting. The

philosophical perspective from which health services are delivered, as well as the

number, distribution, and qualifications of professional personnel are critical to the

structure of health care delivery. Structural characteristics of a health care setting

increase or decrease the probability of quality care (Donabedian, 1980). Several

structural elements of the NH have a direct and significant effect on the process of

providing care to dying residents and thus may influence quality of death (Trotta, 2007).

Two of the most prominent structural issues are philosophy of care in NHs and staffing

issues. This section describes the way in which these two structural attributes affect the

provision of care to dying NH residents.

Philosophy of Care

For decades, many NHs have delivered poor quality care, allowing residents to

succumb to death with minimal intervention. In 1985, the Institute of Medicine

conducted an investigation documenting and publicizing the neglectful care in NHs

(Institute of Medicine, 1986). The findings were used as an argument for the Nursing

Home Reform Act (NHRA), contained in the Omnibus Budget Reconciliation Act of

1987 (OBRA, 1987). The NHRA established minimum quality standards and also set forth a monitoring system. NHs were made formally accountable for the quality of care they provided and were subject to regulatory oversight (Mukamel & Spector, 2003). The NHRA brought about many positive changes in NHs, eliminating much of the negligence observed prior to 1990 (Klauber & Wright, 2001). As a secondary effect, however, it instilled a philosophy of care that does not embrace dying and eventual death as inevitable.

The varying interpretations of the NHRA have undoubtedly influenced research on care of the dying in NHs and perhaps in the absence of research into death itself. The significance of regulations and paperwork required to document complicance can negatively affect the dying experience.(L. C. Hanson, M. Henderson, & M. Menon, 2002) Similarly, institutional philosophy fosters task-focused rather than resident-focused care at the end of life (Wetle, et al., 2005). Family respondents in one study felt that state and federal mandates, which are driven by the NHRA, discouraged palliative care for dying residents (Wetle, et al., 2005). Researchers have also found that the current NH environment does not easily incorporate palliative care, even when desired by dying residents and their families (Kaasalainen, Brazil, Ploeg, & Martin, 2007; Kayer-Jones, et al., 2003). More rigid standards of care under the NHRA were necessary to address serious issues of neglectful care, but the unintended consequences have also led to misalignment of NH philosophy with care of dying residents. This misalignment fails to account for impending death, making quality of death difficult to address.

Nurse Staffing and Education

Appropriate staffing levels and low turnover are associated with high quality care in NHs (Castle, 2009). A national study, however, found that 90% of NHs lack adequate staffing (U.S. Centers for Medicare and Medicaid Services, 2001). Not only do NHs suffer from staff shortages (Wetle, et al., 2005), but they also experience high staff turnover (Castle & Engberg, 2005). Researchers have demonstrated that dying residents benefit from staff taking extra time for activities such as massage or reminiscence (Baer & Hanson, 2000). Yet staff shortages result in little time to provide more than basic care. Furthermore, when dying residents are cared for by staff who know them well, they benefit from receiving individualized care (Munn & Zimmerman, 2006). High staff turnover, however, precludes this from happening. Staff shortages and high staff turnover, therefore, may prevent NH residents from receiving high quality care as they die.

Education of NH staff, particularly in relation to care of dying residents, has also been documented as poor. Nurses at all levels receive little training with regard to caring for dying residents, such as providing individualized symptom relief or sophisticated interpersonal communication (Ersek, Kraybill, & Hansberry, 1999; Kaasalainen, et al., 2007). Many nurses lack the skills, knowledge, and confidence to care for residents at the end of life (Ersek, et al., 1999; Raudonis, Kyba, & Kinsey, 2002). Even when this is not the case, high staff turnover often prevents any lasting effects of ongoing staff education (Raudonis, et al., 2002; Strumpf, Tuch, Stillman, Parrish, & Morrison, 2004).

Inadequate staffing and staff turnover have repeatedly been shown to negatively affect the dying experience for residents (Baer & Hanson, 2000; Kapp, 2003; Kayer-Jones, et al., 2003; Kayser-Jones, 2002; Munn & Zimmerman, 2006; Wetle, et al., 2005).

Nursing assistants in one study stated they were overwhelmed by their workloads and felt

unprepared to care for dying residents (Schell & Kayser-Jones, 2007). In several studies,

family members felt that nursing staff did not have the knowledge or expertise to provide

quality end-of-life care (Munn & Zimmerman, 2006; Thompson, Menac, Chochinov, &

McClement, 2008; Wetle, et al., 2005). In a methodologically diverse body of literature,

staffing issues are not explicitly framed as structural elements affecting the process, and

ultimately outcomes, of care. A multitude of issues around nurse staffing and education

in NHs, however, undoubtedly prevent dying residents from receiving optimal care.

Understanding the way in which these issues affect quality of care for dying residents is

necessary to refine quality of death as a potential outcome.

<div align="center">Process of Care in the Nursing Home</div>

Process is described as the set of activities occurring between residents and

practitioners. Quality of care processes is judged by evaluation of the relationship

between characteristics of care and consequences to individuals (Donabedian, 1980).

Benchmarks for quality care provided to dying NH residents, such as pain management,

personal cleanliness, and family communication with providers, occur within specific

process modalities. Two major processes of care articulated in the literature that

encompass such benchmarks are hospice and palliative care. A third collection of

literature describes the usual care provided to NH residents who happen to die, but are

not necessarily prospectively identified as dying and in need of specialized care. This

may be considered the "null-process" because it does not reflect any intentional process

aimed at improving the quality of care for dying residents. This section will describe the

available evidence regarding processes of care, noting the effects of the structural

elements described above on these processes, as well as the way in which these processes

affect potential outcomes such as quality of death.

Hospice

Hospice is a well circumscribed process of care made possible for NH residents

under the Medicare Hospice Benefit. Hospice care aims to ameliorate symptoms, reduce

unnecessary or unwanted medical intervention, and attend to the psychosocial needs of

both residents and their families at the end of life (Miller, Gozalo, & Mor, 2001).

Interestingly, although there is wide geographic variability, only about 5%-20% of NH

residents receive hospice care (S. Miller, et al., 2004; Miller & Mor, 2001; Reynolds, et

al., 2002). The myriad of barriers to hospice care delivery in NH may explain why so

few residents receive it. The barriers include the establishment of contracts between the

NH and hospice agency (Hanson, Sengupta, & Slubicki, 2005), negotiation for payment

(Hanson, et al., 2005), and certification of a six-month prognosis (Zerzan, Stearns, &

Hanson, 2000). Furthermore, concerns around care coordination between NH and

hospice agency staff (Dobbs, Hanson, Zimmerman, Williams, & Munn, 2006) and the

belief that NH staff provide better end-of-life care than hospice, further limit referrals

(Welch, Miller, Martin, & Nanda, 2008). As a result of these barriers, rates of hospice

use are low in NHs (Petrisek & Mor, 1999) and length of stay on hospice is short (Wetle,

et al., 2005), often less than a week (S. C. Miller, et al., 2004).

In addition to barriers to hospice care delivery in NHs, empirical evidence does

not consistently demonstrate high quality care for residents receiving hospice. In some

studies, enrollment in hospice has been shown to improve pain assessment and

management (Miller, Mor, & Teno, 2003), decrease likelihood of hospitalization in the

last month of life (Gozalo & Miller, 2007), and increase family satisfaction with care

(Baer & Hanson, 2000). Another study, however, found no evidence that hospice

services were consistently associated with improvement of symptom management,

hygiene care, spiritual support, or family satisfaction (Munn, Hanson, Zimmerman,

Sloane, & Mitchell, 2006). One potential reason for these mixed results may be that

empirical studies delineating exactly what constitutes hospice care in the NH have yet to

be conducted. Without delineating processes of hospice care in this environment, its link

to quality may be difficult to establish. Furthermore, despite the fact that hospice care is

intended for its beneficiaries until they die, death is rarely made explicit. Investigation

into the utility of an outcome such as quality of death may shed light on specific process

measures linked to quality care.

Palliative Care

Palliative Care employs a similar philosophy to hospice. It differs from hospice in

that it is not linked to any payment or reimbursement system and does not require a care

team separate from the existing NH care team. In addition, because PC does not rely on a

strict prognostic criterion, it is often described as having more longitudinal leeway than

hospice (National Hospice and Palliative Care Organization). Some NHs have

incorporated PC practices into existing care in a variety of ways, but it is not widespread

(Travis, Loving, McClanahan, & Bernard, 2001). Results of a large national survey

indicate 27% of NHs have some type of special program and/or trained staff in palliative

care and/or hospice care (Miller & Han, 2008). The nature and extent of these practices

and expertise, however, are unknown.

The evidence for PC delivery in NHs is limited. A few reports of small local efforts at sustained implementation of PC exist (Avis, Jackson, Cox, & Miskella, 1999; Levy, Morris, & Kramer, 2008; Powers & Watson, 2009; Strumpf, et al., 2004) Integration of palliative care into current care practices was partially successful, but was coupled with significant obstacles. These include communication difficulties and limited financial and human resources (Avis, et al., 1999; Strumpf, et al., 2004).

What is known about the delivery of palliative care in NHs largely comes from research highlighting barriers to such care. A significant challenge to the integration of PC in the NH setting is that the PC philosophy is not recognized in regulations governing NHs (Zerzan, et al., 2000). Delivery of PC also requires resources, such as additional staff training, that are not often available (Ersek, et al., 1999). Even if these resources are available, PC programs are often not sustainable due to staff shortages and turnover (Strumpf, et al., 2004). These barriers to PC delivery underscore the inherent structural elements of NHs and the barriers imposed on processes of care. In addition to structural barriers, timely recognition of impending death hinders appropriate initiation of PC (Travis, et al., 2002). Furthermore, although broad guidelines for PC exist (National Consensus Project for Quality Palliative Care, 2004), the lack of specific criteria for PC delivery in the NH makes it difficult to implement in such a highly regulated setting (Travis, et al., 2001).

These barriers may result in part from the lack of a consistent definition of PC, and the consequent methodological challenges in studying the effects of PC on the quality of care. Furthermore, because PC has not been explicitly linked to death, its effect on quality of care may or may not be consequential in influencing quality of death.

Whenever barriers are examined, there is an implicit assumption that the PC process is sound and will improve outcomes, if only the barriers could be eliminated. Researchers often assume that PC improves the quality of care (Hall, Schroder, & Weaver, 2002; Reynolds, et al., 2002), but this has not been empirically established. It is possible, however, that the barriers to PC lie in the limitations of the process itself. Lack of a clear and consistent practical definition, however broad, likely prevents sustained efforts at implementation. In addition, PC efforts have not been studied for their effects on the quality of the death experience. If, like hospice, PC is assumingly meant to be delivered until residents die, understanding its effects on the quality of death would likely advance understanding of both the process of PC and the outcome of quality of death.

Null Process

Several papers describe care delivered to NH residents at the end of life when no other explicit process, such as PC or hospice, is superimposed (Hall, et al., 2002; Kayser-Jones, et al., 2003; Reynolds, et al., 2002; Wetle, et al., 2005). In these studies, end of life care represents the care residents received at the end of their lives. End-of-life is merely a term, not a process or an action. Symptoms experienced by residents at the end of life are described, along with hygiene, communication, and overall quality. These articles are representative of the null-process, as no particular process is in place.

Pain and dyspnea are the most commonly discussed symptoms. Reports of dyspnea ranged from 75% (Reynolds, et al., 2002) to 62% (Hall, et al., 2002). Reports of pain ranged from 86% (Reynolds, et al., 2002) to 44% (Hall, et al., 2002). One qualitative study demonstrated inadequate treatment of pain (Wetle, et al., 2005). Elswhere, mention of pain by physicians was notably absent (Brandt, et al., 2005b).

Psychological symptoms are also prevalent at the end of life. Reynolds et al (2002) reported that 44% of residents were anxious, 31% were depressed, and 35% needed more spiritual care (Reynolds, et al., 2002). In a focused chart audit of the last 48 hours of life, a notation of delirium in 29% of residents was found, with no reports of anxiety, depression, or other symptoms (Hall, et al., 2002).

Other important issues at end of life are personal cleanliness and food and fluid intake. Reynolds (2005) reported that 81% of residents had problems in this area, and qualitative studies note that personal care was neglected as residents neared death (Kayser-Jones, et al., 2003; Reynolds, et al., 2002; Wetle, et al., 2005). Kayser-Jones et al (2003) reported that despite residents' desire to eat and drink, they did not receive enough assistance to do so (Kayser-Jones, et al., 2003). This compliments the finding by Brandt et al (2005) that 42% of residents had very little or no fluid intake at the end of life (Brandt, et al., 2005b).

Communication is described from a variety of perspectives. Three studies portray family members' perspectives on communication. One reported dissatisfaction with physician interactions and highlighted poor and untimely communication between physicians and families (Wetle, et al., 2005). In another study, 36% of families reported needing more and better communication (Reynolds, et al., 2002). Hall et al (2002) note that residents and families desire honest, compassionate, and individualized communication. Although discussions with family were documented in 74% of cases, the content of the discussions is unknown (Hall, et al., 2002). Reynolds et al (2002) found 25% of nurses and nurse aides reported needing better communication amongst themselves (Reynolds, et al., 2002).

Attention to physical and psychological symptoms, personal aspects of care, and communication have been identified as benchmarks of quality end of life care (Teno, et al., 2004). While many reports reference quality in some way, connections between findings and overall processes of care are not made explicit (Hall, et al., 2002; Kayer-Jones, et al., 2003; Reynolds, et al., 2002; Wetle, et al., 2005). Furthermore, while the magnitude of symptoms and issues is clear, the wide variability makes interpretation of findings difficult. These shortcomings prevent targeted efforts at understanding and improving the quality of care delivered to residents at the end of their lives. Lastly, attention to death, the obvious and finite end to life, is also absent from this work. Without suitable frameworks and prospective exploration explicitly linking the process of care to quality of death, the outcomes and problems associated with end-of-life care can not be addressed in clinically practical ways.

In two instances, respondents were queried directly about overall quality. Flacker et al (2001) asked physicians, nurses, and nurse aides to rate the overall quality of the resident's death on a four-point scale ranging from 1=terrible/uncomfortable to 4=peaceful. Mean values for this item were 3.68 for physicians, 3.67 for nurses, and 3.72 for nurse aides (Flacker & Kiely, 2003). Reynolds and colleagues (2002) asked two questions of nurses, nurse aides, and family members. First, they asked respondents to rate their overall satisfaction with the quality of care, and second, asked whether or not respondents believed the resident's dying experience was "a good death- how he/she would have wanted it." Sixty four percent of the deaths were rated as "very good" in terms of overall quality, and 58% of deaths were rated as "good deaths (Reynolds, et al., 2002)." It is difficult to interpret these findings given the largely negative evaluations of

care at the end of life. The vague nature of these questions on overall quality may partially explain this incongruency.

The work of Flacker et al (2001) and Reynolds et al (2002) are limited in several ways. The authors fail to provide evidence of a theoretical foundation for their items querying overall quality. Thus, the anchors applied in Flacker et al's (2001) study have no contextual meaning and the definition of a good death in Reynolds et al's (2002) study lacks theoretical validity (Flacker & Kiely, 2003; Reynolds, et al., 2002). Second, the authors do not link these overall questions on quality to specific end of life care processes. Absence of this connection limits the potential for improvements in process to be reflected in outcomes. Finally, the authors omit interpretation or discussion of their findings on overall quality items in light of other study findings. This leaves readers to draw independent conclusions about the relationship between the items and their overall meaning. This omission is particularly interesting given the positive scores on overall quality in light of the largely negative findings reported with regard to care at the end of life.

<div align="center">Outcomes</div>

Measurable outcomes are typically used to assess the quality of care. Donabedian (1980) describes outcomes specifically as changes in the patient's (resident's) current and future wellbeing which can be directly attributed to antecedent health care (Donabedian, 1980). Literature that addresses outcomes of care for dying NH residents is limited and varies methodologically and analytically. In some cases the language of outcomes is used explicitly (Engel, Kiely, & Mitchell, 2006; Forbes-Thompson & Gessert, 2005; Munn & Zimmerman, 2006); just as often, it is not (Caprio, et al., 2008; Chan & Kayser-

Jones, 2005; Kayser-Jones, 2002). Explicitly identified outcomes include family

satisfaction and quality of dying; implicit outcomes include a good death and the

experience of dying. Studies describing a good death and the experience of dying are

included here because of their conceptual connection between the antecedent experiences

of receiving care in a NH setting and the results of those experiences.

Family Satisfaction

Family satisfaction with care at the end of life in NHs has been explored by three

groups of researchers. Engel and colleagues (2006) administered the Satisfaction With

Care at the End of Life in Dementia scale to proxies of severely demented residents to

identify factors associated with satisfaction with care. Thompson and colleagues (2008)

conducted focus groups with bereaved family members of NH residents to explicate the

factors contributing to satisfaction and dissatisfaction with end-of-life care. Daaleman

and colleagues (2008) conducted structured post-death interviews with family members

to assess the relationship between the structure and process of spiritual care and family

ratings of overall end-of-life care.

Although each used a different approach, all stress the importance of

understanding the specific determinants of family satisfaction. Family satisfaction is

highly dependent upon recognition of the resident's declining health status (Engel, et al.,

2006; Thompson, et al., 2008); timely and adequate communication (Engel, et al., 2006);

(Thompson, et al., 2008);and the provision of spiritual support (Daaleman, Williams,

Hamilton, & Zimmerman, 2008).

Understanding the determinants of family satisfaction for care provided to NH

residents at the end of life is important, since family members often function as proxies

and are also clients of NH care. Applying family satisfaction as the outcome measure of

quality of care for residents, however, is limited in several ways. First, it neglects the

resident's perspective. Families may aptly report their level of satisfaction with personal

experiences regarding the care of their dying relatives, but superimposing their

perspectives onto the resident's experience may lead to false understandings. Second, it

is a retrospective measure, limited by the family member's ability to remember specific

events. Third, family satisfaction is influenced by family members' level of involvement

with their loved ones' care. Amount and intensity of family interactions with the NH

care team thus may affect reports of satisfaction. Fourth, the time periods for asking

family members to report satisfaction is variable, which limits the collective validity of

the findings at this time. Finally, the family satisfaction literature does not deal with the

event of death itself, limiting understanding of quality of death. For these reasons, family

satisfaction represents a skewed outcome of care at the end of life.

Good Death

The concept of a good death has emerged as a potential outcome of end of life

care in the NH. Three empirical studies examine the good death, but only one explicitly

frames it as an outcome (Munn & Zimmerman, 2006). Hanson and colleagues (2002)

conducted focus groups with NH staff and identified three central elements of a good

death: individualized care, caregiver teamwork, and advance care planning (L. C.

Hanson, et al., 2002). Munn and colleagues (2008) conducted focus groups with

residents, family members, and staff. Across all groups, a good death was one of

comfort, dignity, and closure (Munn, et al., 2008). Munn and Zimmerman (2006) also

investigated the good death via interviews with staff and family members, and organized

their findings according to the structure-process-outcome framework. Findings showed

that a good death is dependent upon structural components of consistent and adequate

staffing, as well as adequate staff training and a homelike and intimate facility

environment. Significant process elements were staff "being there" and displaying

empathy (Munn & Zimmerman, 2006). The variety in findings and process-outcome

conceptualizations of a good death demonstrates its potential as an outcome in end-of-life

care research. This variability, however, precludes the good death from systematic

application in such research.

Application of the good death as a potential outcome to improve care provided to

NH residents as they die has several limitations. Perhaps the most significant limitation

is absence of an adequate, consistent, theoretically grounded definition. The lack of a

consistent connection to specific care processes also limits the potential for systematic

and measureable improvements. Furthermore, dichotomizing "good" from the alternative

("bad") may hinder targeted efforts at process improvement because these terms disallow

the application of a continuum. Inherent in these limitations is the lack of association to

quality. While individual evaluation of the goodness of an experience is valid, the

judgmental tone of the good death limits the potential for external appraisal. Culturally

predicated judgments about dying well will likely influence the utility of the good death

as a barometer for evaluating the care provided to NH residents as they die.

Quality of Dying

Measurement of quality of dying in the NH setting is an emergent area of

research. Munn and colleagues (2007) created the only known instrument solely for the

purpose of assessing the quality of dying for those living in long-term care (LTC)

environments (NHs and assisted living). The Quality of Dying in Long Term Care

(QOD-LTC) is adapted from the QUAL-E (Quality of Life at the End of Life) and

includes the perspectives of patients in settings other than hospitals (Munn, et al., 2007).

The QUAL-E is a 31-item scale validated for prospective administration among

terminally ill cognitively intact patients receiving care in ambulatory care settings. The

QOD-LTC is an 11-item scale retrospectively administered to staff and family members

of deceased LTC residents. Family members and staff were contacted a minimum of

eight weeks after a resident's death to complete the instrument. Instructions regarding

what time period of the resident's life to consider prior to death, for example, the last

month of life, were not specified.

The QOD-LTC has been used in one empirical study since its debut. Caprio and

colleagues (2008) used it to better understand the relationship between physical

symptoms (pain and dyspnea) and the quality of dying in LTC settings (Caprio, et al.,

2008), although the QOD-LTC does not specifically address pain or dyspnea. Nearly

half of the residents experienced pain or dyspnea, but perceptions of the quality of dying

were not strongly related to the presence of these symptoms. Interpretation of these

findings may be skewed because assessment of symptoms was done by staff and family

members several weeks after a resident death. Clearly, there is need for further

investigation of the relationship between symptom experiences and overall quality of

dying.

Constructing items to assess existential human phenomena, such as dying, is

undeniably difficult, and the QOD-LTC is therefore limited. Munn and colleagues

(2007) omit inquiry about pain and other symptoms based on results of factor analysis.

The clinical significance of these symptoms and their connection to quality is clearly apparent (Hall, et al., 2002; Reynolds, et al., 2002). The instrument also lacks items on the moment of death and immediate post-death period. This gap in questions makes the boundaries of "dying" unclear. Although the QOD-LTC is psychometrically sound, its omissions render it potentially inadequate to fully assess quality of dying for residents in the NH setting. Finally, the extensive adaptations call the theoretical foundation of both the items' representativeness of dying residents' experiences and the notion of quality into question. The adaptations described above render the instrument a depersonalized objectification of the residents' experiences of dying, with no explanation of how these items measure quality.

The Experience of Dying

Kayser-Jones and colleagues have contributed to understanding of the dying experience for NH residents by observing care and interviewing those involved in the care, including the residents themselves. Lack of attention to cultural needs and inadequate or inappropriate communication emerged as significant issues for dying residents (Chan & Kayser-Jones, 2005; Kayser-Jones, 2002). Inadequate staffing was also identified as negatively affecting the dying experience (Kayser-Jones, 2002). Schell and Kayser-Jones (2007) found that while empathy allowed for the delivery of compassionate care by CNAs, organizational conditions often stymied their efforts (Schell & Kayser-Jones, 2007).

While the work by Kayser-Jones and colleagues has provided insight into the dying experience for NH residents, their methodological and interpretive techniques expose gaps in understanding and limitations in the applicability of current knowledge.

The ethnographic perspective applied to this research allows for the rich portrayal of the research participants' experiences. It does not, however, contribute to the construction of a theoretical frame from which future inquiry could be based. Furthermore, this work may be interpreted such that quality of the dying experience depends on the following factors: level of attention to cultural needs; adequacy of communication between providers and residents/family members; adequacy of staffing; and the ability of direct care staff to provide empathetic care, among other things. Without explicitly framing these findings in terms of quality and outcomes, systematic improvement in the care provided to NH residents as they die is difficult. Finally, the lack of focus on death itself prevents explication of the ultimate outcome of dying.

Brandt and colleagues (2005) assessed the last days of life for NH residents using prospective administration of the Palliative Care Outcomes Scale (PCOS) by proxies (Brandt, et al., 2005a). Physicians were asked to identify residents whom they believed had six weeks or less to live. There are several interesting points about this study. First, the residents were not receiving any specific palliative care, yet the quality of care in the last weeks of life was evaluated according to the PCOS, a measure specifically designed to evaluate PC. Second, while 471 residents were included in the study, 272 residents also died within six weeks and were thus incorrectly omitted from the study, as noted by the authors. This highlights the difficulty in determining an accurate prognosis, and its potential impact on the validity of this research. Third, this study is one of the first to evaluate outcomes of care using a validated instrument, but the instrument items are not linked to any specific care processes. While the findings contribute to knowledge

development, the weaknesses of this work limit its utility in guiding practice and

research.

Forbes-Thompson and Gessert (2005) conducted a qualitative case study of two

NHs in order to explore the phenomenon of dying in a naturalistic setting (Forbes-

Thompson & Gessert, 2005). The NHs were purposively selected for their divergent

philosophies and care practices. To evaluate the residents' experience of dying, they

used the outcome measures of residents' satisfaction with care and quality of life while

approaching death (Forbes-Thompson & Gessert, 2005). In the NH focused on

compliance rather than residents' individual needs, the residents were dissatisfied and

reported poor quality of life. In the NH focused on its clients and their needs, residents

were more satisfied and reported higher quality of life. Results demonstrated that

divergent NH structures and processes of care led to substantively different outcomes.

This research aptly applies Donabedian's framework to guide inquiry and demonstrate

the impact of structure and process of care on outcomes. Nonetheless, its relevance is

limited by the constraints of the case study method. Additionally, this work includes the

resident's perspective, which is often missing from end of life research. While naming

their outcome "quality of life while approaching death" may have been most acceptable

to residents who participated in the study, this term contributes to the ongoing ambiguity

with regard to terminology in the body of literature that frames quality of death.

Conclusions

The literature outlined in this chapter demonstrates societal awareness of the

importance of dying in a NH. Yet, it only tangentially represents understanding of the

collective experience of death in the NH. Furthermore, it demonstrates narrow and

fragmented attempts to systematically improve this experience for residents who die in

NHs. Four significant limitations plague this literature. First, critical terms, such as

dying, death, palliative care, and end-of-life, lack consistency and definition. Second, the

term quality is applied liberally with assumed and undefined characteristics. Third, most

methodological approaches lack precision, making tenuous assumptions based on limited

scope and reported findings. Fourth, the collective literature is atheoretical. Each of these

is further discussed below.

<center>*Imprecision With Regard to Terminology*</center>

The literature is bound by specific terminology, yet there is little attention to

precise definitions or conscious choices in applied language. This is most evident in two

instances: use of the word dying, and use of the words palliative care, hospice, and end-

of-life care. At times, dying appears to mean the action of death, thereby including the

event of death itself. Other times, dying implies an imperceptible time period prior to

death, and appears not to include the event of death. Unclear use of the term dying

prevents understanding of the exact time period being described. In addition, it fosters

assumptions about death itself, because death is not made explicit. Unclear use of the

word dying thus renders our understanding of death in the NH tenuous, and creates

difficulty in explicating the quality of it.

Empirical work discussing hospice care, palliative care, and/or end-of-life care

often fails to provide clear definitions of these care processes. For example, Sloane and

colleagues (2008) describe the experience of dying and provision of PC for LTC

residents with and without dementia, yet fail to define PC. In a list of their survey items,

PC interventions are operationalized as "special attention to moving and positioning" and

"received hospice services." As another example, Levy and colleagues (2008) state *PC* consultations were provided by a *hospice* agency, and *hospice* consultations were provided by *hospice* agencies. The presence of two types of consultations indicates there is a difference between hospice and PC, but the difference is not explained. This is particularly confusing given both types of consultations are provided by hospice agencies.

Inherent assumptions with regard to these terms are also present. End of life care is often assumed to mean something more than what it is by definition-simply the care that residents receive at the end of their lives. In addition, some authors use the terms end-of-life care and palliative care or hospice care interchangeably (Evans, 2002; Powers & Watson, 2009; Raudonis, et al., 2002; Reynolds, et al., 2002; Travis, et al., 2002). Implying that end-of-life care includes special interventions that may fall under the guise of palliation, for example, skews the meaning of end-of-life care. This lack of consistency leads to misunderstanding about what phenomena are being examined, what services are provided to residents, and with what outcomes. Is end of life care always to include palliation? Is it not? These questions remain unanswered.

Other assumptions made about PC are that it improves outcomes, and that those with identified terminal illnesses are receiving it. Reynolds and colleagues (2002) assumptively translate the presence of issues such as pain and inattention to hygiene into palliative care needs. This translation implies that PC would improve the residents' symptoms and meet their needs. Although PC likely improves the dying and death experience for residents, this has not been empirically established. Additionally Mitchell et al (2006) and Hall et al (2002) both make the assumption that residents with terminal

cancer are receiving some form of palliative care, simply because they have an obvious terminal illness. Furthermore, both groups of authors base their conclusions on this assumption.

No Definition or Conceptualization of Quality

Much of the literature framing quality of death uses the term quality. Interestingly, very few provide a definition or theoretical foundation for the meaning or definition of quality. As a result, quality is an assumed characteristic with assumed attributes. The lack of specificity with regard to quality is most evident in the work of those studying "quality of dying" and those who study the experience of dying and ask questions about overall quality (Caprio, et al., 2008; Flacker & Kiely, 2003; Munn, et al., 2007; Reynolds, et al., 2002). Absence of a foundational understanding or definition of what is meant by quality renders this work difficult to interpret since both researchers' and participants' interpretations of quality likely vary as they ask about and respond to questions.

Methodological Limitations

The methodological approaches framing quality of death in the NH are limited in a variety of ways. First, much of it is retrospective. Although retrospective design may be useful in eliciting reports about death, death is rarely explicated. When the events of death or immediate post-death activities are made explicit, they are only tangentially addressed. For example, Sloane et al (2008) query the domain "care of the imminently dying patient" for which the variable was "circumstances of death." The meaning of this variable was, in reality, place of death, which provides little information regarding the actual circumstance. Another limitation of retrospective design is the reliability of

participants' recall. Some researchers waited several months to contact study participants (Engel, et al., 2006; Reynolds, et al., 2002; Wetle, et al., 2005). This technique severely limits the recall of accurate and detailed information, yet much of what is reported about dying in the NH is elicited in this way.

A second methodological limitation is that the resident's perspective is rarely elicited directly. Some authors claim to report on the residents' experiences of dying, but in reality, they report on staff or family members' perspectives of the residents' experiences of dying (Brandt, et al., 2005b; Hanson, et al., 2008; Mitchell, Kiely, & Hamel, 2004). Framing findings in such a way perpetuates the assumption that it is acceptable to know one's experience through the eyes of another.

Thirdly, qualitative methods employed lack open-ended, inductive approaches. Interviews were often structured or semi-structured leaving little opportunity to discover information not contained in pre-conceived questions (Flacker & Kiely, 2003; L. C. Hanson, et al., 2002; Reynolds, et al., 2002). Ethnography may achieve thick description of situations, but does not permit abstraction at the level of theory generation (Chan & Kayser-Jones, 2005; Kayser-Jones, 2002; Schell & Kayser-Jones, 2007).

Absence of Theory

The most significant limitation in this literature is the lack of any theoretical frame. Very few articles utilized a theoretical framework to guide their inquiry. Furthermore, none of the studies reviewed contributed to theory from which quality of death in the NH could be understood. Lack of a theoretical foundation to guide inquiry into complex phenomena such as the quality of dying or the good death severely hinders understanding of their meanings and limits applicability in future work.

Summary

This chapter provides a review of the literature circumscribing quality of death in the NH. Using Donabedian's quality framework exposes both implicit and explicit outcomes, both of which are tied to poorly described processes that often fail to acknowledge structural boundaries. Furthermore, the absence of theory and widespread imprecision with regard to pivotal concepts and terms limits any collective understanding of quality of death in the NH. These limitations underscore the need for a study aimed at generating a sound theoretical foundation explicating quality of death in the NH. Current understanding of quality of death, a concept generated via an inductive analysis of palliative care literature, indicates that it is dependent upon structural and process elements of care (Trotta, 2007).

This emergent mode grounded theory study prospectively engaged a well-described palliative care population with the aim of eliciting and portraying the resident perspectives. It also utilized an a priori definition for the meaning of quality and focus explicitly on death. This Grounded Theory, informed by SI and SWAT, refines and verifies the concept of quality of death in the NH. This was done via close examination of the interpersonal and symbolic process of palliative care and the effect of the NH as an arena on the process. This Grounded Theory has significant potential to both improve evidence based care and guide future inquiry.

CHAPTER 3: METHOD OF INQUIRY

Introduction

Grounded theory in the emergent fit mode (GTEF) guided this inquiry into quality of death in the NH. This study delineated dimensions of quality of death in the NH and further refined and clarified the concept. The final product is a practical theory grounded in data generated from qualitative event analysis (QEA) of situations around death in the NH. This chapter begins with a description of GTEF, highlighting its applicability to the study purpose and aims. A detailed explanation of the study procedures follows. This includes sampling technique, adaptation and application of QEA, data management, and data analysis. Attention to maintenance of methodological and theoretical rigor follows. This chapter concludes with a detailed discussion regarding the protection of study participants and ethical concerns.

Exploration of quality of death in the NH requires methods and means to uncover a phenomenon that may be obscured by implicit assumptions and overshadowed by current understanding of death in the NH and perceptions of the quality of death. Quality of death in the NH is currently a retrospectively constructed preliminary concept. It was theoretically constructed from published data on palliative care in the NH. As such, it is largely bound by perceptions of researchers and clinicians (Trotta, 2007). A sequentially valid method of inquiry should provide sufficient latitude to prospectively explore and portray individuals' experiences of death in the NH and illuminate elements of quality (viz. acceptability, legitimacy, and equity) within it. It should also provide sufficient structure to guide the analytic process and generate theory, starting with the preliminary concept of quality of death.

Design

Grounded theory in the emergent fit mode (GTEF) facilitated inquiry into quality of death in the NH. Broadly, grounded theory is a qualitative approach to design, data collection, and analysis. The grounded theory process guides inquiry into a phenomenon or concept about which little is known, with the goal of generating theory that is grounded in data (Strauss & Corbin, 1998). GTEF is a form of grounded theory that is most applicable when a theory has already been developed about a particular phenomenon. It is used to verify and refine preliminary findings into a formal Grounded Theory (Artinian, 1986). With its roots in symbolic interactionism, GTEF relies on the emergence of meaning via human interaction and social process (Blumer, 1969). This inquiry arose from a symbolic interactionist perspective, and relied on my awareness and understanding of the concept of quality of death in the NH as I developed theory in the emergent mode (Strauss & Corbin, 1998).

GTEF can employ a variety of methods or techniques for data collection. This study relied on three iterative qualitative techniques to discover data: qualitative event analysis, constant comparison, and theoretical sampling technique. Qualitative event analysis (QEA) is a data collection strategy that facilitates focus on events related to quality of death in the NH (Happ, Swigart, Tate, & Crighton, 2004). An event is something of importance to the investigation (Kayser-Jones, 2002). In this study, I observed events and generated data in the form of field notes. Some examples of events were a resident's death, a resident's transfer to the hospital, or an episode of acute illness.

Preliminary analysis of field notes were subjected to constant comparative technique, an inductive process of interrogating the data (Charmaz, 2006). Constant

comparative technique served a variety of purposes. As it relates to data collection, the results of constant comparison guided the construction of a theoretical sample.

Theoretical sampling technique is a sampling method whereby subsequent sources of data are selected based on emerging theory (Glaser, 1978). Theoretical sampling technique begins with a purposive sampling strategy. Purposive sampling strategy is necessary initially because no data yet exists from which to frame a theoretical sample. Once preliminary analysis is completed, theoretical sampling strategy replaces purposive sampling strategy. As such, theoretical sampling technique guided me in the selection of additional study participants and events for QEA. This iterative process continued until theoretical saturation (Charmaz, 2006) on the primary themes around quality of death in the NH was achieved. Through GTEF, the collective experience of death in the NH was preserved and reflected in a formal Grounded Theory, *Cultivating Knowing and Relationships*.

<div align="center">Setting</div>

The study took place at Community Geriatric Center (CGC). CGC is a 700 bed NH located in New York, NY. CGC provides care to a diverse population. Residents at CGC receive short-term rehabilitation, long-term custodial care, dementia care, and ventilator care. Residential care units are comprised of mostly two-bedded rooms, and some single-bedded rooms. There are 17 care units at CGC. Each unit has a large room that functions as a recreational room and a dining room where residents eat their meals. In addition to the resident care units, CGC has two warmly decorated lobbies, one in each of its two buildings, an auditorium with a stage where large events are held, and an activities room where residents take part in cooking, music, arts, and crafts. CGC also

has a chapel, a gift shop, and a cafeteria. There is an outdoor space behind the buildings with a landscaped garden, a walking path, and benches.

Palliative care (PC) is integral to the philosophy of care delivered at CGC. CGC has an interdisciplinary PC team that meets every other week to discuss current and ongoing activities. These meetings also serve as a forum for discussing potential ethical issues or difficult clinical situations that arise in the delivery of PC. Team members are representatives of their respective disciplines, and act as liaisons communicating concerns, issues, and suggestions from their peers. Nonetheless, PC is not delivered by the PC team per se. The purpose of the team is to facilitate and support the delivery of PC by the CGC staff. No additional outside staff or services are utilized in the delivery of PC.

Anyone can suggest a resident as one who is appropriate to receive PC. Such suggestions are usually voiced at care plan meetings, but can occur at any time. Residents may be deemed appropriate for PC for a variety of reasons. They are generally identified as close to death and have in some way expressed the preference for care that favors palliation of symptoms rather than diagnosis and invasive treatment. The philosophy of PC at CGC fits well with the current conceptualization of quality of death (Trotta, 2007) in that it acknowledges death prospectively and embraces the fluidity of the transition from life to death. Although the concept of dying may surface when a resident is deemed appropriate for PC, determination of dying is not used as a precursor to its implementation.

The choice of PC is designated on the health care record by physicians or nurse practitioners, signaling a philosophical shift in the delivery of care. At that time, the PC

philosophy usually drives changes to a plan of care to maximize comfort, although there

is no prescribed timeline or protocol for instituting aspects of PC. Residents receiving

PC are not segregated in any way from residents receiving traditional care. At CGC, PC

is individualized to meet the unique needs of residents and their families. In addition to

traditional biomedical approaches to comfort, the PC philosophy at ICG also incorporates

non-traditional therapies such as music, aromatherapy, and therapeutic touch. PC also

includes comfort for family members, for example, a recliner chair for extended stays and

meal coupons for the cafeteria. All employees – both clinical and non-clinical – a receive

continuing education by the PC team to ensure the philosophy permeates all dimensions

of resident experiences at CGC.

In summary, CGC fosters a community atmosphere with utmost consideration for

the residents' care and comfort. The staff demonstrates a high level of commitment to

the CGC mission and vision, and families and residents report a high level of satisfaction.

CGC's philosophy on and approach to the delivery of PC make it unique among

institutions of similar purpose and capacity. The prospective acknowledgement of death

for residents receiving PC make it ideally suited as a setting for verification and

refinement of the concept of quality of death.

Procedures

This section provides a detailed account of the study procedures. It begins with a

description of the process for gaining entrée into the research setting and the daily lives

of those who inhabit the NH arena. The process for participant selection and technique

for sampling is outlined, along with a description of the QEA method and reasons for

adapting it to meet the needs of this study. QEA procedures and exit from the field

follows. Attention to data management and a thorough discussion of procedures for data analysis conclude this section.

Gaining Entrée

Three and a half years ago, I was a nurse practitioner at CGC and a member of the PC team. I remained in contact with the Vice President for Care Services (VP) at CGC and was invited to conduct my study at the institution. After a prolonged absence, I began my re-entrée into the setting for the purposes of this study by attending a PC team meeting. Many staff members from various disciplines were invited to attend. At that meeting I introduced myself and described the proposed study, gaining support and trust of the team and those who ultimately deliver PC. The study was explained as one that aimed to describe the process of PC for residents in the program. Resident experiences would be observed during events involving them or related to their care. The VP also introduced me to the chief executive officer (CEO) and directors of the departments. The VP assigned one of the Community Directors to be my contact person at CGC. This person was instrumental in facilitating my entrée to the units where I collected data, personally escorting me to the residential care units and introducing me to the charge nurses and other staff. This formal introduction signified the support of my presence as a researcher by the PC team, the medical director, director of nursing, and the administration. I was given a CGC photo identification, with my title labeled as "Temporary Researcher." I was granted permission to park free of charge in the guarded parking lot on-site. Lastly, I was given a cubicle in a shared office with a locked cabinet for my unlimited use during the study period.

I employed several strategies for gaining trust and acceptance in the NH environment, as I believed a high degree of rapport was required for implementation of a study such as this one. First, I dressed in a conservative manner, mirroring those who wear street clothes in the facility, so as not to call undue attention to myself. Second, I answered questions about my presence openly and directly, and shared some personal information about myself when appropriate. Third, I offered my assistance in instances where staff members were clearly in need, as these gestures aided in developing trusting relationships (Jorgensen, 1989). Some examples of these instances included going out of the room to get a pair of gloves for a CNA and handing a CNA a towel during a resident's bed bath. In these instances, I had to balance the boundaries of being an investigator versus providing helpful immediate assistance. For example, although I was asked for my clinical opinion in several instances, I never intervened in a clinical or therapeutic way.

Gaining entrée in social research is profoundly affected by the way the researcher is perceived by participants. I was visibly pregnant during the data collection period, which undoubtedly shaped the way I was received by those who inhabit the NH arena. Week after week, my growing abdomen served as a topic of conversation, and thus a source of entrée. I believe it facilitated my persona as caring, maternal, and essentially non-threatening. Most female staff members engaged me in conversation about my expectant baby, and I feel they were better able to identify with me given many were also mothers. I was often the recipient of advice and caring gestures, for example being told to drink water, and being offered a seat at the nurses' station where seating is limited. In summary, gaining entrée for this study was a sequential process that began with entrée

into the physical setting of the NH and lead to entrée into the daily lives of those who regularly inhabit the environment.

Participant Selection and Sampling Technique

This study utilized two types of participants, index residents and secondary participants. Index residents were residents at CGC receiving PC. Secondary participants were defined as individuals involved in events that occurred with index residents. These included clinical and/or non-clinical staff at CGC and family members and friends of the residents. At the outset of the study, there were approximately 90 residents in total receiving PC. These 90 residents were dispersed throughout the facility, yet some units had higher concentrations of PC residents than others. I decided to begin by concentrating on the four units with the highest numbers of residents receiving PC. Although it was ultimately not necessary, I had formulated plans to expand the study to additional units if necessary.

Participant Selection via Purposive Sampling Strategy

Letters were sent to the identified proxies for the residents receiving PC on the four study units. Reaching out to the residents' proxies was important given they would ultimately be providing informed consent on behalf of the residents due to cognitive impairment (see consent section). The purpose of the letter was to inform these proxies that a research study would be taking place and they may be contacted to provide permission for the residents' participation. The letter was sent on CGC letterhead paper and signed by the CEO, indicating CGC's support of the study. It also contained my name and phone number if anyone desired to call for more information. Shortly after the

letters were mailed, I received phone calls from five family members, four of whom decided to provide consent for their loved ones' participation in the study.

In tandem with the letters to proxies, I began my initial enrollment of secondary participants. Purposive sampling strategy guided me in the selection of initial secondary participants. I visited each of the three shifts on each of the four study units to introduce the study and enroll staff members as secondary participants. I chose to do this so that when events occurred during the data collection period, lengthy consent procedures would not interfere with the unfolding of the event and resident care. I also hung flyers on the four units with a short description of the study and my contact information. I informed the staff that they could call me at any time with questions or notify me if something was occurring with any of the residents in the study. Forty-one staff members enrolled during this initial enrollment of secondary participants. One caveat in understanding this strategy is that some staff who prospectively enrolled did not ultimately participate in the study.

Purposive sampling allowed me to further target index residents based on the study purpose and aims. I capitalized on the opportunity to speak with family members of PC residents who were visiting their loved ones. In that way, I could obtain consent in person rather than over the telephone, facilitating trust and entrée. Further index residents were enrolled via telephone consent by their proxies (see consent section). One requirement for enrollment of index residents was that they had a proxy designated in their medical records. In addition, I worked to achieve variability on resident characteristics such as gender, age, race, ethnicity, primary diagnosis, and length of time on PC.

With each enrollment of an index resident, I purposively prospectively sampled secondary participants. Some family members agreed to consent in the instance that they would be involved in an event over the course of the study. I also sought the participation of the primary nursing staff caring for the enrolled residents, as well as the physicians, nurse practitioners, dietitians, social workers, and community directors who covered the four study floors. At this point, an initial sample of index residents and secondary participants was enrolled using purposive sampling strategy, and data collection began. Preliminary analysis of this initial data drove further sampling via theoretical sampling strategy.

Participant Selection via Theoretical Sampling Strategy

As I began to decide where to sample based on emerging theory, theoretical sampling strategy replaced purposive sampling strategy (Coyne, 1997). Theoretical sampling, a foundational aspect of grounded theory, is an iterative process whereby data are collected and analyzed, and the preliminary analytic findings drive selection of the subsequent sample (Glaser, 1978). Theoretical sampling, therefore, generates data that will clarify and develop emerging themes, culminating in empirical theory generation (Charmaz, 2006). Questions spawned by constant comparison of initial data directed selection of subsequent index residents and critical events for EA. Theoretical sampling technique also drove interviews with individuals deemed key informants. Key informants were selected based on their role and/or knowledge regarding a particular resident or PC at CGC in general.

Participant Description

Twenty five index residents and 95 secondary participants in total enrolled in the study. Ultimately, 21 index residents and 59 secondary participants comprised the final participant set. As noted earlier, due to prospective enrollment, not all who enrolled in the study actually participated in the study. Of the secondary participants, there were 20 CNAs, eight nurses, eight doctors or nurse practitioners, five social workers, five non-direct care workers (unit coordinators, community directors, physical therapists, and dietitians), four individuals in administrative positions, and nine family members or friends. The average age of the residents was 89 and 18 (86%) were female. Their ethnic backgrounds were varied; six (28.5%) were Caucasian, seven (33.3%) were African American, seven (33.3%) were Hispanic, and one (4.9%) was Native American.

Data Collection Method-Qualitative Event Analysis

Qualitative event analysis (QEA) is a form of focused data collection around a particular event, activity, or issue occurring with a research participant. QEA elicits detailed description and analysis of events via a variety of data sources: observation, interview, and medical record review (Happ, et al., 2004; Kayser-Jones, 2002). As opposed to minute-to-minute life activities, "events" differ in that they are highly predicated on human interaction and often have circumscribed boundaries of time, place, and participants (Happ, et al., 2004). QEA was chosen for this study because it facilitated verification and refinement of quality of death through analysis of events.

Adaptation of QEA for This Study

While QEA offered an efficient and effective method of data collection, I realized that it would have to be adapted to meet the needs of this study. I identified three key reasons why QEA required adaptation to meet the needs of this study. First, whereas

traditional QEA studies focus on events of a singular type, for example, weaning from mechanical ventilation, this study would have varied event types, all falling under the umbrella of PC. Second, in traditional QEA studies, the event type is predetermined. In this study, some events could be predetermined, but in order to adhere to the tents of grounded theory, I required the flexibility to allow for the incorporation of unanticipated events. Third, the timing of events in traditional QEA studies could often be anticipated or planned, again as in weaning from mechanical ventilation. In my study, potential events could occur at any time. At the outset of the study, however, the exact method of adaptation could not be fully determined. As a result, the adaptation took place as events unfolded, and relied on scholarly discussion with methodology experts and the preliminary theory of quality of death. Specifically, QEA required adaptation with regard to discovery and definition of events.

Early discovery of events. Once an initial group of approximately four or five residents and likely secondary participants was enrolled, I began to employ strategies to discover events for observation. I began by spending time in open spaces such as the nursing station and the dining room, casually talking to people and observing what was going on. This allowed me to get to know the staff that cared for the residents enrolled in my study and understand the daily routine that took place on the units. In my initial days at the NH, I discovered events that I termed "obvious and regularly occurring activities," such as the feeding of residents and provision of hygiene care. Initially, however, I did not conceive of these activities as "palliative care events," and therefore I did not anticipate including them as "data." Rather, my initial plan was to conduct fieldwork on these activities in order to facilitate deeper entrée, establish rapport with staff, and hone

my data collection skills. After reflecting on these early experiences, however, I

considered the possibility that they could in fact be events of PC. My mentors and I

concluded that in its broadest sense, any interaction that was taking place as the resident

is deemed to be receiving PC could potentially be a PC event.

With a broad conceptualization of what constituted an event in place, I needed to

determine what would not be defined as an event for the purposes of this study. Guided

by symbolic interactionism, I determined that feeding of residents, for example, was

predicated on an interaction or exchange between people. On the other hand, mealtime,

where a resident was either not eating or feeding himself, would not be defined as an

event. Similarly, a CNA providing hygiene care to a resident was considered an event,

but a resident alone in his or her room was not an event. This determination of how an

event would be defined provided a strong theoretical foundation for subsequent data

collection. At this point, however, I needed to develop strategies to discover other events

that were occurring with the residents and those with whom they interact.

Advanced discovery of events. After several weeks, I achieved a sufficient level of

entrée and understanding of the NH process. This led to the development of several more

sophisticated strategies to discover events. First, I took advantage of the fact that I was

invited to attend the facility-wide daily morning meeting. In this meeting, a verbal report

tallied the residents who were considered sick, those who fell, those who died, and those

who were transferred to the hospital. I used the meeting to identify events of interest.

Resident transfers and deaths are also written in a binder, so I could look back and see if

any residents in the study were discussed on the days I was not at the NH. Second, I

learned that on each unit, the nurses kept a log of resident issues to be addressed by the

doctor or nurse practitioner. Third, the nurses also kept a 24 hour report sheet used as a

communication hand-off from shift to shift. Residents "on report" were typically

receiving an antibiotic or some other non-standing therapy, or were being watched for a

particular reason. Fourth, building on my initial discovery strategy of spending time in

open areas and talking with people, I specifically asked the charge nurse and the CNAs

caring for my study residents if anything was going on with them on that particular day. I

asked pointed questions in an effort to determine if an event was unfolding. In some

instances, staff members called me about an event.

Defining events for this study. Data collection around events using EA techniques

requires careful consideration of various context and situation specific issues. In QEA,

defining the temporal and environmental boundaries of an event is critical (Happ, et al.,

2004). I found defining personal and theoretical boundaries was also critical. I

anticipated that decisions with regard to definition may be required as the study unfolded,

but I could not anticipate exactly what they would be. These emerged as a result of the

social process of care in the NH, and were addressed with respect to the study purpose

and aim. There were three main points to defining events for this study: determining

temporal parameters, determining personal parameters, and separating events versus

allowing them to be "one."

Traditional events in QEA have a clear or somewhat clear beginning and end. In

fact, noting the length of time of the event is often an important piece of data. These

parentheses are usually imposed by the researcher, but also closely mirror the clinical

situation. In this study, conflicts often arose with regard to when an event started and

ended. An example of this is a resident hospitalization. One may consider the start of

this event to be when the resident leaves the facility. Another may consider it to be the time when the issues leading to the hospitalization began. In that case, there may be differing perspectives as to when the issues began and what they were. As a result, both exact start and stop times of events and total length of time of an event were recorded to capture varying temporal parameters on an event. I maintained focus on the content of the event rather than temporal parameters.

Addressing the issue of temporal parameters of events directly led to the second point of definition, determining personal parameters. As I interviewed event participants, they had different perspectives regarding the temporal boundaries of an event. These perspectives also differed from my own interpretation of the event start and end. Because this issue was unique to my study, I discussed it with my committee's methodological experts. We determined that based on the aim of this study, the events may begin and end at different times depending on whose perspective it is. Imposing a universal beginning and end from which participants should provide their perspectives would theoretically limit the data.

Once I made the determination to relax temporal boundaries and allow personal parameters to individually emerge, a third issue regarding definition arose. Separating events versus allowing them to be "one" was an unanticipated issue at the outset of this study. Events that occurred sequentially with a resident, such as hospitalization and death, appeared at first to be two distinct events. At times when I interviewed secondary participants, however, they described events in relation to each other, as if they were one continuous event. Again, I relied on the support of my methodological experts and the overarching aim of the study. We determined that events needed to emerge theoretically

from the participants' perspectives. Forcing participants to focus on one "event" or another would theoretically limit the breath and depth of the data. Therefore, if participants described what may be considered two discrete events as one event, they were labeled accordingly in the data set.

Missed events. Dealing with missed events required consideration with regard to both discovery and definition. Obviously, events took place with the index residents on the days that I was not at the NH, precluding my ability to observe them. In traditional QEA studies, however, observation is the primary data source, and all events are observed. In adapting QEA to meet the needs of this study, I relied on the study aim and design to decide to include events that I did not observe. GTEF guided verification of the concept of quality of death. Therefore, I looked for the opportunity for verification in events. I also carefully chose these events based on the impact and meaning they held for the individuals involved.

A variety of events took place during my absence from the NH setting. After several days away, using the methods for discovery of events noted earlier, I learned of events that occurred with the residents in the study. I briefly spoke with individuals involved in the events and reviewed the medical records. If the event did not seem to have a lasting impact on the resident or secondary participants, nor did it seem to directly contribute to the verification of quality of death, I did not pursue it. Some examples of events I chose not to pursue were a visit to the surgical clinic for a wound debridement, an episode of a UTI, and an episode of hypoglycemia.

The events that I chose to pursue, despite being unable to observe them directly, were a hospitalization and eight deaths. The example of the hospitalization depicts my

reasoning for pursuing this type of event. When I returned to the NH after several days

away, staff members were obviously deeply affected by a resident's hospitalization.

When I arrived on the unit, the nurses and CNAs asked me if I had any information about

the resident's condition. They spoke openly about their concern for the resident's well

being and hopes for a safe return to CGC. In addition, if the resident's family member

called to provide an update, the staff shared that information with me. This event clearly

had meaning and was important to pursue. The desire to obtain and share information

coupled with expressions of care and concern underscored the importance of this event,

and supported my decision to pursue it.

I pursued events I did not directly observe by reading the medical record to get a

sense of who was involved and what happened. Next, I interviewed those who wrote

notes in the medical record. This was typically the nurse, doctor, and/or nurse

practitioner. From there, I interviewed other staff members, typically CNAs. If possible,

I also interviewed family members. I kept memos of thoughts and reactions to the

interviews, and paid particular attention to information that was either consonant or

dissonant among the interviews.

QEA Procedure

The procedure for data collection in QEA involves collecting data from three

main sources: observations, interviews, and medical record review. Observations

detailed my perspective on the event. Informal interviews served to clarify my

interpretations of the event, and also clarify and enhance analytic findings as they

emerged. Medical records were reviewed for written information about particular events,

as this information represented the writer's interpretation of a particular event.

Information obtained from medical record review also served to clarify and enhance the

analytic findings. This triangulation of data sources (e.g. observation, interview, and

record review) is a foundational aspect of QEA, as it strengthens the quality of the data

and depth of the analysis (Happ, et al., 2004; Kayser-Jones, 2002). A fourth data source

was interviews with key informants. These were conducted at the end of the study to

further verify the emerging theory. Finally, I kept memos throughout the process,

detailing my methodological and analytic thoughts and decisions.

Event observation. Once consent was obtained from everyone present, I situated

myself as close as possible to the event while minimizing the potential for interference

with the event (Happ, et al., 2004). During an event, I manually recorded short field

notes in a small notebook, if I felt doing so would not be construed as obtrusive or

disrespectful to those in the immediate vicinity. As I observed the event, I avoided

making generalizations or interpretations of what I was observing. Rather, I recorded

concrete sensory details, for example, smells, sounds, and actions of

participants(Emerson, Fretz, & Shaw, 1995). I recorded as many verbatim quotes as

possible as I was observing events. I also made note of particular references or word

choices by the participants. I kept timelines of occurrences within events. As soon as

possible after events, I dictated formal detailed field notes into a voice recorder using my

jottings as a guide.

After the event, I verbally recorded a field note, using my notes written during the

event as a guide. In field notes, I strove to record a highly detailed account of what was

happening, focusing on the details of human interaction and their meanings (Blumer,

1969), particularly as they related to the preliminary theory of quality of death. I noted

how staff members communicated with residents verbally and non-verbally, how they

positioned themselves in relation to the residents, and how they interacted physically with

the residents. I also noted how staff members and others communicated, paying

particular attention to tone of voice, word choice, and non-verbal communication. The

final QEA field note described immediate precursors and consequences of the event, in

addition to relationships among participants and how they potentially influenced the

event (Happ, et al., 2004). In summary, QEA was applied to construct a highly detailed

or thickly described (Geertz, 1973) account of each event.

Capitalizing on the advanced strategies for event discovery, I was able to observe

many spontaneously occurring events. Some of these could be anticipated, such as

hospitalization or resident death, but some were not, such as an episode of hypoglycemia,

and a resident with progressively poor nutritional intake. I continued to employ these

strategies and had great success in discovering events. This adapted process of discovery

revealed the need to also adapt QEA with respect to defining events.

Informal interviews. As I stated earlier, theoretical sampling technique dictated

the initial selection of secondary participants for informal interviews by purposive

sampling strategy. After initial data were analyzed, subsequent secondary participants

were chosen using theoretical sampling strategy. Guided by this theoretical sampling

technique, I selected participants for interview based on questions that emerged during

the event. Informal interviews took place as soon as possible after the event to maximize

the participants' recall.   These interviews took place in private locations on the

residential care units (e.g., in an empty resident room or the supply room) or another

location off the unit (e.g., a participant's private office or empty room), depending on

time and availability of the participant and availability of private space. These interviews

lasted anywhere from 3 minutes to over an hour. My questions focused on activities that

transpired within the critical event. For example, I asked secondary participants to

explain his or her rationale for a certain decision or for further explanation regarding

word choice in discussing the event with a family member or colleague. Interviews with

family members, friends, and administrators took the longest Data collected via informal

interview was voice recorded using a hand-held recorder.

   Medical record review. I reviewed the medical records of enrolled residents for

information documented in relation to an observed event. Information documented in the

medical record served to clarify data collected during an event. I read the medical notes

related to the event verbatim into my voice-recorder in a private location. I noted the

date and time of the documentation in relation to the event. Finally, I noted the absence

of written information in the medical record related to an event. Enrolled residents'

medical records were also reviewed for demographic data and other descriptive

information.

   Key informant interviews. Towards the end of the study, I identified several

individuals as key informants. I chose key informants based on their knowledge about

and relationship to the provision of PC at CGC. I contacted these individuals and set up

meetings for the interview at a specific time and place. Key informant interviews were

audio taped and lasted between 30 to 120 minutes. My questions to these key informants

were driven by the results of constant comparison and early analytic findings. I looked to

confirm or disconfirm ideas from early analysis via these interviews. I also sought

broader perspectives on the philosophy and delivery of PC, given some key informants held senior and administrative roles at CGC.

Memos. Memos were written during the data collection phase, and continued through the analysis phase. Memo keeping is a critical practice in grounded theory research and serves several purposes. Dating and categorizing memos (methodological, theoretical, and observational) served as an audit trail for analytic decisions made throughout the research process. Memos also served to develop early codes and eventually guided the categorization of codes. They also aided in reducing bias in perspective and maintaining methodological rigor by forcing constant questioning at every step of the research process. Memos detailed my thoughts, interpretations, questions, and analytic decisions (Strauss & Corbin, 1998).

Exit from the Field

Exit from the field is a phase that begins when the objectives of the study are satisfied (Jorgensen, 1989). In this case, it began when theoretical saturation on the major themes was reached. To reach theoretical saturation, Strauss and Corbin (1998) propose data collection continue until (1) no new or relevant data emerges within a category, (2) the properties and dimensions of each category are well developed and even, and (3) the relationships among categories are well established (Strauss & Corbin, 1998). Constant comparative technique, an analytic tenet of grounded theory, drove decisions related to theoretical saturation. Continued scrutiny of memos, which provided an audit trail of the data analysis process, also served to determine theoretical saturation.

When theoretical saturation was nearly complete, I focused only on events that contributed to the emerging theory. These were primarily death events. I spent the final

two weeks following up on these events and conducting interviews with key informants. EA during this phase served to clarify and verify emerging analytic findings. As I reached theoretical saturation, I began to inform the staff on the four data collection units that my study was ending in the near future. I also informed the VP, medical director, and director of nursing. Once I set a date for my last week at the nursing home, I let everyone know that I would bring refreshments for each shift on the four study floors to express my gratitude for participation and facilitation of my study.

The end of data collection naturally and fortuitously coincided with the last month of my pregnancy. At times. I found it difficult to explain that I would not be returning after the baby was born. I took pictures with some staff members with their permission, and wrote heartfelt thank-you cards to the staff of each shift on each unit. I also verbally thanked everyone for their participation. I received many hugs and even a few baby gifts. Staff members requested that I keep in touch and send pictures of the baby. Several family members requested to see the final written product in the future.

Data Management

Brief field notes from observations of events were manually recorded in a notebook. Full field notes were then spoken into my digital voice recorder, guided by the brief notes taken during the event. Data contained no identifiable information. Informal interviews in connection with events and key informant interviews were voice recorded. Due to the possibility that sound recordings of participants' voices could serve to identify them, I took precautions to maintain the safety and security of both the digital voice recorder and paper notebook by carrying them with me or locking them in the file cabinet in my cubicle.

Voice recorded data were transcribed by Same Day Transcription Service, Inc. Voice recorded data were downloaded to Same Day Transcription Service, Inc. via their secure internet server. The company transcribed the data verbatim, and uploaded a text document to my password protected secure server account. Once transcriptions were uploaded, I checked them for accuracy against the original voice recordings. Next, I removed or changed any potentially identifiable information and entered the transcriptions into NVivo 8, a qualitative data analysis software program housed on my laptop computer, which is password protected. I also entered manually recorded data from my field notebook and memos, into NVivo 8. Finally, I saved copies of both voice-recorded data and transcribed data on a password protected external back-up hard drive at my home.

In order to manage the multiplicity of data that were collected around index participants, I developed a tracking system to keep track of the events and the participants involved. This system also maintained identity protection of their identity. Data were labeled with a code sequence that connected participants to events. The code sequence began with the event number, then the resident's number, then the number of any secondary participants. A master list of the participants' names and code numbers was kept in a secure location separate from the research data.

Data Analysis

Data analysis in grounded theory is an interpretative process that relies on techniques of constant comparison, and begins at the time of data collection (Charmaz, 2006). Constant comparison is an analytic technique used to maintain theoretical sensitivity throughout the entire coding process. Coding, a basic technique of grounded

theory, was used to interpret the data. Coding is a three-phase process whereby the data are taken apart, categorized, and reconstructed in order to generate theory (Charmaz, 2006). Phases overlap at critical junctures in the analysis, and transition to the next phase is dictated by the results of constant comparison and quest for theoretical saturation.

In this study, I applied GTEF to verify and refine the preliminary concept, quality of death. As events were discovered and data collection progressed in tandem with analysis, I sought evidence of verification or disconfirmation. Of the 21 residents who participated in the study, eight of them died during the data collection period. These eight death events were among 42 events of varying types that comprised the entire data sample.

Analytic Focus on Death

The death events occurred randomly and were interspersed among other events. Early analysis pointed to the significance of residents' deaths over other events. Interviews with participants around death events revealed rich and detailed accounts of the deaths. In addition, participants provided retrospective accounts of the residents' lives and their relationships with the residents. QEA allows for several options for categorizing data, leading to deeper analysis and subsequently richer findings (Happ, et al., 2004). After I completed data collection and was reaching the level of theoretical coding, I chose to focus the Grounded Theory on the eight death events.

Additionally, theoretical coding revealed a relational intimacy in interviews and observations with CNAs that was not evident with other types of secondary participants. During interviews, CNAs expressed intense emotion about the recently deceased

residents. They also spoke in a personal way when describing the death event. Not only did they describe the event from their individual perspective, but they also described what the event meant to them, and recounted the entire cultivation of their relationship with the resident. Theoretical sampling of data from the other events, primarily events that involved the residents who died, illuminated and refined emerging themes. In summary, an analytic focus on interviews with and observations of CNAs within the eight death events allowed me to achieve thick description in constructing this Grounded Theory.

Constant Comparison

Constant comparative technique guided the coding process. It involves recording all possible characteristics and features of particular codes, and then subjecting them to questioning to reveal subtle similarities or differences, thus advancing the analytic depth among particular codes (Charmaz, 2006). Constant comparison also relies on scrutinizing definitions, dimensions, and variants of words and language. Constant comparison significantly contributed to my determination of theoretical saturation of categories, simultaneously exposing areas where further data collection was needed. I also used constant comparison to minimize the effect of personal bias in interpretation. Constant comparative techniques were applied throughout the entire analytic process.

Coding

Open coding. Open coding involves line-by-line analysis to extract key words or phrases from the raw data. Selected open coding took place weekly after several days spent at CGC collecting data. Initial open coding immediately generated questions for constant comparison. As early open codes were interrogated, I began to place them in preliminary categories (Walker & Myrick, 2006). Once several preliminary categories

emerged, I transitioned to axial coding. Open coding continued, however, until all events theoretically chosen for the analysis were coded. Ultimately, several thousand open codes were generated.

Axial coding. As data collection continued and preliminary categories of open codes emerged, axial coding began to overlap with open coding was phased into the analytic process. Axial coding involves further categorization of open codes by rearranging and condensing them into conceptually related groups (Strauss & Corbin, 1998). Constant comparison led me to sample both participants and events as axial codes emerged. Application of constant comparison and theoretical sampling technique ensured that emerging ideas about quality of death were theoretically grounded. For example, the idea of a CNA "knowing" a resident emerged early on in analysis. This preliminary idea was based on early observations of CNAs feeding and providing hygiene care to residents whom they had known for many months or years. They seemed able to anticipate what residents wanted and needed based on the longevity of the relationships. Constant comparison led to a search for instances where CNAs did not know the residents with whom they were working. This is also termed a negative case. Theoretical sampling drove me to approach specific CNAs for participation as they embarked on care of an unfamiliar resident. Observation of such an event confirmed my initial conclusions regarding the CNA who "knows" the resident for whom he or she is providing care.

Theoretical coding. Once a substantive number of axial codes are generated and open coding is nearly completed, theoretical coding is phased into the coding process. Theoretical coding links axial codes via their theoretical relationships (Strauss & Corbin,

1998). Theoretical coding begins to take place as data collection is nearing completion.

As theoretical codes are emerging, data collection becomes increasingly selective. For

this reason, I looked for events with the intent of achieving theoretical saturation on the

major themes that were emerging around quality of death. For instance, at this point in

data collection, I purposefully chose not to pursue the event of a resident's visit to the

surgical clinic for sutures to a finger laceration. During this period, I also conducted key

informant interviews, which helped to support and clarify emerging themes. Theoretical

coding concludes with the formation of a conditional matrix to explicate the resultant

Grounded Theory. This matrix depicts the complex social relationships that exist

between and among the theoretical codes that emerged through the analytic process.

Maintenance of Rigor

Maintenance of rigor preserves the trustworthiness of the research findings and

interpretation of data (Davies & Dodd, 2002). I maintained rigor in this study by

adhering to the principles associated with scientific integrity as they refer to naturalistic

inquiry. These features have various synonyms, but generally refer to the concepts of

credibility, authenticity (Whittemore, Chase, & Mandle, 2001), and reflexivity (Finlay,

2002). This section will detail the way in which these concepts were addressed and

preserved throughout the course of the study.

Credibility and Authenticity

Maintaining credibility and authenticity were critical to this research study.

Credible findings are those that are derived from thorough and sufficient data collection

and analysis (Charmaz, 2005). Authenticity refers to the accurate portrayal of the

participants' experiences as well as situational phenomena (Whittemore, et al., 2001).

Attention to credibility and authenticity began with careful implementation of grounded

theory methods. Use of constant comparative techniques ensured all theoretical

possibilities present in the data were explored and addressed. Timely and detailed

memos served as an audit trail documenting all methodological and analytic decisions. I

had frequent meetings with members of my dissertation committee to ensure thorough

and accurate application of both grounded theory and QEA was upheld.

Credibility and authenticity were also maintained through the use of member

checks. Member checking generally involves sharing the researcher's interpretations and

analysis of data with study participants in order to seek validation from the original

source (Janesick, 1994). In this study, I implemented two versions of member checks.

First, when questions arose about the meaning or interpretation of participants' words or

behavior during an event, I requested clarification from the individuals regarding my

interpretation. Second, I interviewed key informants who had specific knowledge and

experience with palliative care at CGC.

Reflexivity

Grounded theory methods required me to become as fully integrated as possible

into the process of death in the NH. In this context, pure objectivity was impossible to

attain, and thus, positivistic truth is impossible to report. Reflexivity refers to the

investigator's scrutiny of personal involvement in the research process (Charmaz, 2006).

Simultaneously, reflexivity also refers to the scrutiny of interpretation of and assumptions

about events. Many social researchers struggle with integration into the research

environment. Because I was welcomed so generously into the lives of my participants, I

relied heavily on reflective practice to maintain my stance as an investigator. I developed

a dialectic of reflective introspection and reflexive questioning. Theoretical memos detailed my reflective practice (Johns & Freshwater, 2007). In these memos, I noted how I thought my presence affected a situation, especially if reference was made to me and my purpose during an event. I also recorded my thoughts and feelings about particular events in order to maintain reflexivity, and limit my own personal biases from shaping the way in which I documented events in my field notes. In these situations, I reviewed my memos and field notes with my dissertation chair. She challenged me to look deeper into my biases and interpretations to ensure they were fully explored and documented.

One particular event highlights my attention to reflexivity. A resident who spoke an eastern European language was in obvious pain. I was standing in the hallway, and witnessed her begin to cry out loudly. The event moved to the resident's room, with two nurses, a CNA, and me following. Later a doctor and a physical therapist who served as a translator joined the event. Before the translator arrived, the nurses immediately looked to me for direction. They knew I was present because the resident was enrolled in my study and that I was a researcher, but they also knew me as a nurse practitioner. The resident was in obvious distress, so I struggled with making a suggestion that could help the resident, yet risk changing the natural course of the event. In my clinical opinion, the resident was having chest pain and I feared an impending myocardial infarction. One of the nurses directly asked me what they should do. I responded with the question, "Does she have a cardiac history?" I felt that rather than telling them what I thought they should do, which was to give nitroglycerin, it would be less intrusive to help them think about what type of pain she could possibly have.

As the pain event unfolded, it was obvious that my presence affected its course and outcome. It would have been impossible for me to stand in the small room and remain a pure observer. I practiced reflexivity during and after the event by saying as little as possible, calling my dissertation chair immediately after the event to debrief, recording my thoughts in memos, and then recording my field note.

<div align="center">Protection of Human Subjects and Ethical Considerations</div>

Protection of human subjects and attention to strict ethical standards are core components of every research study. Human subjects or study participants require varying degrees of protection depending upon the risks imposed by participation, and their level of vulnerability. Similarly, while ethical standards such as the protection of privacy and confidentiality are important in every study, this study also required unique ethical considerations. This section details the consent procedures and provides a discussion of the ethical considerations required for comprehensive protection of study participants.

<div align="center">*Protection of Study Participants*</div>

This study was approved by the Institutional Review Board (IRB) of the University of Pennsylvania under expedited review. CGC accepted the University IRB's approval. This study posed minimal risk to participants. Informed consent was obtained for all participants. I enrolled two distinct groups of participants in this study, index residents and secondary participants. Each group required a distinct consent process.

Consent Process for Index Residents

At CGC, according to the VP, all of the residents on PC at the time of data collection had some degree of cognitive impairment. Although varying opinions exist,

there is currently no consensus regarding fluctuating capacity to consent over the course

of a longitudinal study, and when exactly to involve a proxy decision-maker (Wendler &

Prasad, 2001). Based on critical evaluation of relevant literature (AGS Ethics

Committee, 1998; Wendler & Prasad, 2001) and discussion with an ethicist, a member of

my dissertation committee, I decided to seek proxy consent for index residents.

All residents targeted for enrollment in the study were required to have a proxy

decision maker. Proxies were identified by CGC, and were documented as the primary

decision-maker in the resident's medical record. I received a spreadsheet of the residents

receiving PC on the four study units with their proxies' names and phone numbers. I

spoke with most proxies over the phone and obtained verbal consent. Arrangements for

the delivery of a copy of the consent document were made with proxies on an individual

basis. In some instances, proxies were present at CGC. In these cases, I reviewed the

verbal consent document with them in person, and gave them a copy. A total of 26 index

residents were enrolled in the study.

In addition to their recommendations regarding the use of proxies, Wendler and

Prasad (2001) also explored assent and dissent among cognitively impaired research

participants in clinical research. I again sought guidance from my dissertation

committee, and ultimately adhered to Wendler and Prasad's (2001) recommendation with

regard to assent. To obtain assent, I explained as much of the research plan as possible to

the index resident, referring to the verbal consent script used to obtain consent from the

residents' proxies. I obtained assent at the time of enrollment, and also at the time of

each event. If a resident expressed dissent, I planned not collect data around the

unfolding event. After three expressions of dissent on three separate occasions, I planned

to disenroll the resident from the study. During data collection, however, no residents

expressed dissent to participate in the study or my presence during any events.

Consent Process for Secondary Participants

As described earlier, this research involved family members or friends of the

resident and staff, whom I termed secondary participants. Written consent was obtained

from all secondary participants. Recruitment of secondary participants took place in two

ways. First, many secondary participants enrolled prospectively during my initial visits

to the units to announce the study, as described in the section on gaining entrée. For this

process, I described the study to the staff on each of the three shifts on each of the four

study units. I read through the consent document and answered any questions. I gave

each person in attendance a copy of the consent document. As this process was

completed in a group atmosphere, I stressed rights to privacy and urged all those

considering participation to take as much time as they desired in reviewing the study

materials. Some signed the consent form immediately, some returned it to me within a

few days, and some did not enroll at all. When an event eventually took place, I

reminded those who had already consented to participate about their status and briefly

outlined their rights as participants and protection of personal information. During each

event, no secondary participants who had prospectively enrolled declined to participate at

the time of an event.

Other people who were not prospectively enrolled were approached for

participation as an event was about to take place. Most of the secondary participants I

approached in this manner had some knowledge about the study and had previously seen

me or met me due to my frequent presence at CGC and efforts during the entrée phase.

In these instances, I informed potential secondary participants that the resident was a study participant, and that I would like their permission to observe their interaction with the resident and possibly speak with them about the event. Some of these individuals were present at my initial presentation, and required only a brief review of the consent document before enrolling. For those who had not heard my presentation, I reviewed the document completely and obtained their signature. In two instances, CNAs granted me permission to observe them and speak with them, but did not want to sign the consent document. In these cases, I collected data on the event, but informed them that I could not use the data unless they enrolled via signing the document. They ultimately did enroll, but this raised an ethical question about the vulnerability of CNAs. I discuss this matter of vulnerability in detail below.

Ethical Concerns

Privacy

Protection of study participants' privacy was upheld to the best of my ability. I also enlisted the participants themselves in the protection of their own and others' privacy. NH environment is a highly social community where many people know each other. Most staff on the four study units knew of each other's participation in the study. In addition, the design of this study required me to reveal the residents' status as a study participant to other secondary participants.   To ensure privacy to the extent possible, I did not openly discuss any details about my study with anyone who was not directly involved or did not need to know the information. I also encouraged secondary participants not to discuss any aspect of their participation in the study with anyone. No

concerns with regard to protection of privacy were expressed to me at any point during data collection.

Confidentiality

Confidentiality was also maintained via several modalities. I kept only one written copy of the document that detailed the residents' names and proxys' names and phone numbers. This document was either on my person or in a locked drawer at all times. The information I collected from the residents' medical records was entered directly into a spreadsheet on my computer, which is password protected. On this spreadsheet, the residents were identified by code number only. A master list of the residents' names and code numbers was kept separate from their demographic and medical information. Any personal information collected during this study was kept confidential and all data were de-identified. Participants were given pseudonyms, and titles were used only in situations where a title could not serve as an identifier.

Moral and Emotional Distress

McCarthy and Deady (2008) describe moral distress as an umbrella concept that captures the experiences of any individuals who are morally constrained (McCarthy & Deady, 2008). For example, nurses could express feeling constrained in their roles due to lack of voice in hierarchical decision making or lack of resources to best care for the residents. Family members could experience moral distress through their inability to adhere to a loved one's advance directive. Emotional distress, on the other hand, refers to a study participant's own surfacing of emotions as a result of participation in the study. Participants may possibly cry during interviews, or express other signs of emotion.

I anticipated that events and conversations around death would elicit moral and emotional distress among some study participants, and appropriate plans were in place to address these issues. Particularly for CNAs, however, moral distress did not surface as I prospectively anticipated. Ultimately, moral and emotional distress were rooted in their compassion and empathy for dying residents. I did not expect to encounter such profound human concern for dying residents. The following excerpts reveal the moral struggle and emotional responses of CNAs who repeatedly usher residents to their deaths:

Just the fact that you're here and you have a heart and you met them and you became friends with them and you know them, it's like this person becomes a part of you somehow. Even though this is not your family member, but they actually become a part of you and when they do pass on it's really painful. A lot of people don't realize that, but it is (participant #92).

No one was there to hold his hand. That's why I hold his hand. I hold his hand. The way he hold my hand, he makes me feel that he is lonely. He was lonely. Once somebody's going this way, you need somebody beside him. Right? Even though you write something down, like when I'm going to go don't give me this or don't give me this (referring to advance directives or living will), but this is a human being right? He needs love. He needs, you know, comfort or something like that (participant #51).

Contrary to my anticipation, CNAs and other participants did not require intervention from me to quell their moral and emotional distress. Rather, it was the appreciation and respect they received from their coworkers and residents' family members, and their knowing that they had a positive effect on the resident's life, that contributed to their perseverance in a job that elicits such profound moral and emotional responses. This study exposes the need for deeper understanding of the precursors to moral and emotional distress. It also calls attention to the need for recognition of the way moral and emotional distress surfaces among individuals who provide personal care to dying people.

Coercion and Fear of Repercussions

I anticipated that some CGC staff members may feel coerced by their peers or superiors to participate in the study. Additionally, they may fear repercussions both from declining to participate and from dissemination of study findings. Although coercion and fear of repercussions are serious ethical issues, detecting them is difficult. In this study, I was alert for possible cues that participants were feeling coerced. This may be certain facial expressions, body movements displaying unease, or verbal hesitancy. In order to combat coercion, I continually stressed to both participants and potential participants that participation was completely voluntary, and they could withdraw at any time. Furthermore, that participation had no bearing on job status at CGC. I also continually informed everyone that I was not asked to come to CGC to observe their practices and report deficiencies, nor would my findings be shared with any supervisors.

During prospective enrollment, I encountered a situation that I felt reflected coercion. A CNA appeared hesitant to enroll despite the fact that several of her peers were enrolling. While her coworkers were handing me their signed consent forms, she held on to hers and did not make eye contact with anyone. The nurse said to her, "oh just sign it," so the CNA signed and handed me the document, but I sensed her reluctance. I smiled and thanked everyone, as I tried not to draw attention to this scenario. Several days later, I approached the CNA privately and reiterated that participation was voluntary, and that she could withdraw her consent, and I would not inform anyone that she withdrew. She declined to do so and stated that she wanted to be in the study. In the end, this CNA did not participate simply because no events took place in which she was involved.

In a few other instances, CNAs expressed fear of repercussions based on the information I was collecting about what they were doing with residents. Although I had stated on many occasions that the information I collected would not be shared with anyone else, including their superiors, concerns still surfaced. In response, I developed a strategy to mitigate fear of repercussions. For example, during a bathing event, I openly described what type of data I was collecting; I was not focusing on how many washcloths the CNA used, but rather the manner in which she approached the resident and the resident's response. At the end of the event, I shared my notes with the CNA. In some instances, I decided not to take notes at all. I believe these strategies contributed to a relaxed and trusting data collection environment.

While I anticipated the potential for coercion and fear of repercussions and had plans in place for their mitigation, I did not fully appreciate their potential ethical impact. When compared to the protection of privacy and confidentiality of research participants, protection against coercion and fear of potential repercussions receives little attention. Further, little evidence is available to guide researchers on how to handle such issues. At the outset of the study, I conceived of cognitively impaired residents as being a vulnerable group in need of protection. Ultimately, however, I believe the CNAs were equally if not more vulnerable than the residents. Traditional characteristics of CNAs such as low socioeconomic status, low education level, and low professional status within NH care structure contribute to their vulnerability. As this realization surfaced, I diligently worked toward developing and maintaining a trusting relationship with the CNAs and to limit the consequences of their vulnerability.

Emotional Distress

While I was initially concerned about emotional distress, especially among residents and their family members, I quickly found that residents were in general not apparently distressed. Even more compelling was the satisfaction that their family members seemed to derive from participating in interviews and providing me with meticulously detailed accounts of their loved ones' lives before they came to reside at CGC. Most emotion expressed in these interviews was tempered with happy reminiscence and with gratitude for participation. Conversely, as I note above, some CNAs appeared emotionally distressed and fearful about the consequences of participating and in being observed during enactment of their roles in caring for residents. In each case, I was able to reassure concerned and distressed CNAs and did not stop data collection for emotional distress.

Adverse Events

Adverse events are those that are considered unanticipated and/or clinically dangerous. Although unlikely in this research study, I proactively decided that I would cease data collection and intervene immediately if I felt the resident was in immediate and serious jeopardy. Additionally, I planned to stop enrollment or data collection if I felt a violation of a participant's privacy or confidentially had occurred. While I was fortunate that no clinical emergencies occurred during the study, I believe that my close attention to ethical standards contributed to the fact that there were no adverse events in this study.

CHAPTER FOUR: FINDINGS

Introduction

"Cultivating knowing and relationships" represents the basic social-psychological process of CNAs who care for dying nursing home residents. Findings indicate that as CNAs engage with residents, they intentionally undergo a process of knowing that spans concrete and existential layers. Through knowing, CNAs deliberately and carefully construct a reality where personal relationships are cultivated with residents and gratification is achieved. As residents die, CNAs maintain the integrity of their relationships with residents by transcending boundaries inherent in the professional context in which this Grounded Theory (GT) is situated. In transcending boundaries, the CNAs deepen their knowledge of each person for whom they provide care to cultivate a relationship that sustains often minutely detailed personalized care.

This emergent mode GT describes the major themes that transpire within the CNA experience of caring for dying nursing home residents. The chapter begins with a description of how CNAs cultivate early concrete knowing. This knowing aids the CNA in understanding the resident. Next, reciprocity is introduced as the medium through which the inter- and intrapersonal processes of cultivating personal relationships and achieving gratification unfold. Existential knowing facilitates CNAs' acknowledgement of residents' impending deaths and further nurturing of the relationships. Finally, CNA reflections on the experiences of resident deaths represent the transition from letting go of one relationship as relationships begin again with new residents. *In vivo* codes are used at times as section headings to portray the impact of the precise words used by the CNAs.

Examples from narratives accompany interpretations to enhance understanding of the

qualitative context in which these findings exist.

<div align="center">Concrete Knowing: Cultivating Understanding</div>

Within the professional context of the nursing home, knowing became

immediately evident in observations of interactions between CNAs and residents.

Several layers of knowing emerged in this analysis. The layers found early in the CNAs

relationships with their residents are more obvious and tangible while the deeper layers

are more existential in nature. The layers of knowing ultimately exist simultaneously, but

their inherent complexities result in cultivation at varying rates. Through concrete

knowing, CNAs cultivate an understanding of residents. Knowing resident likes and

dislikes is the first layer, and is a function of the assigned CNA-resident relationship.

Knowing resident behaviors, the second layer, is discovered through sustained interaction

with and careful observation. Knowing the resident as a person, the third layer, spans

concrete and existential knowing. In a concrete sense, it requires the CNA to discover

personal traits of the resident. This section describes the initial three tangible or concrete

layers of knowing.

"We Discovered He Liked Sweet": Knowing Residents' Likes and Dislikes

Knowing resident likes and dislikes**,** or preferences for certain things, is the first

layer of knowing to develop in the CAN-resident relationship. From the very first CNA-

resident encounter, the CNA begins to learn what the resident likes and does not like.

Expression of preferences can be immediately detected by observing what the resident

eats and noting how the resident responds during hygiene care. CNAs obviously treat

residents with respect as they perform their duties, but social attachments have not yet

formed. As a result, knowing at this point is used mostly to facilitate the CNA's

completion of his or her work.

Knowing resident likes and dislikes proved very useful during feeding. CNAs

described the development of tactics to get the resident to complete a meal. Knowing

resident likes and dislikes clearly makes it easier for CNAs to accomplish feeding and

bathing of residents. For example, when Mr. Lesser first came to CGC, he was able to

feed himself, but ate very little. One CNA noted, "We discovered that he liked sweet."

After that discovery, assurance was made to include some sweet food in every meal, so

that he would eat as much as possible.

Ms. Verde is an evening shift CNA and cares for Mrs. Ada Schultz. Mrs. Schultz

has severe dementia and requires spoon feeding. She eats pureed meals, drinks thickened

liquids, and occasionally needs to be reminded to swallow. The following excerpt from a

field note describes my observation of Ms. Verde feeding dinner to Mrs. Schultz.

Ms. Verde is putting a dab of ice cream on the edge of the spoon. I asked her why she is
doing that and she says, "The resident does not like the food very much, but when she
tastes the ice cream first she will eat the food." So I asked the CNA how she figured this
out and she said that she has been taking care of this resident for five years and she has
gotten to know how to get the resident to eat her dinner. At one point Mrs. Schultz says
"no more, no more." So Ms. Verde stops for a minute and rubs her hands, and then gives
her another spoonful, and the resident continues to eat it. When Ms. Verde puts the food
in Mrs. Schultz's mouth she occasionally does not swallow. Ms. Verde says, "Come on
Ada swallow, swallow," and then she will swallow. Ms. Verde smiles and nods and says,
"Good girl, good girl." So she sort of encourages and coaxes her, it seems. Then after the
resident eats all of her food, Ms. Verde mixes cold thickened juice and milk together in a
cup. She said she knows the resident likes cranberry and she mixes them together in the
cup so the resident can also get her calcium, and feeds them to the resident with a spoon.
Ms. Verde turns and says to me, "It is good when you know the resident."

Knowing the residents' likes and dislikes is also important in anticipating resident

responses to CNA care, future requests, or future actions. In the field note excerpt below,

Wilma puts a heavy fleece jacket on Mrs. Peterson and a handkerchief on her head,

though this outfit seems too warm given the summer weather. She knows what the

resident likes, and though the resident is not explicitly expressing a present desire, Wilma

knows the resident will request it later.

She put socks on the resident and then sat her up and went into the closet and got a pullover fleece jacket, which is not something I have ever seen a nursing home resident wear. She put the fleece over the resident's head and put the arms in. To me it seemed a little bit thick based on the weather, but I asked the CNA, "Does the resident like this?" She said, "Oh, yes. If you don't put it on now, in the dining room she will tell you that she is cold, and then you will just have to put it on later, and it's harder to put it on when she is already up." I asked her why the resident does not wear just a regular sweater like most of the residents do, and she said, "She does not like those knit type of sweaters. This really keeps her very warm. The other sweaters did not keep her warm enough, so her family bought this and she really likes it." Then, she told me that the resident likes to wear a handkerchief on her head, so she always puts it on before the resident leaves the room, otherwise the resident will say later that her head is cold.

In conclusion, as CNAs get to know the residents to whom they are assigned, they

begin to learn resident likes and dislikes. Despite limited verbal ability, residents are

often able to readily express likes and dislikes through actions and reactions, especially

during mealtime and hygiene care.

"She Gets Tired Early": Knowing Resident Behaviors

After spending time with residents, CNAs uncover a second layer of knowing,

knowing resident behaviors. Over time and through careful observation, CNAs come to

understand the meaning of resident behaviors. Through knowing resident behaviors,

CNAs could anticipate resident needs. This makes the process of caring for a resident

more productive, and reduces frustrations that could arise when CNAs do not know

resident needs. The following is an excerpt from a field note concerning Ms. Amarillo

and her provision of evening hygiene care to Mrs. Galveston. Mrs. Galveston has severe

dementia and can only vaguely express her preferences.

At 4:30pm, Ms. Amarillo started to get Mrs. Galveston ready for bed. I thought this was a little early to be getting a resident ready for bed, and I was skeptical of her reasoning. I asked her, "How do you know if Mrs. Galveston is ready for bed?" She said, "Oh well she has been up all day and she says that she is tired. She really does not look tired, but if I tried to keep her up in order to eat dinner in the dining room, she will become very tired sitting in her wheelchair and she will not eat dinner. She will just push it to the side." I found this very interesting because typically nursing home staff are instructed to keep residents up as long as possible, and that eating in a social environment is understood to be better for their quality of life than eating alone in their rooms. I responded, "So if Mrs. Galveston gets to bed earlier, she will eat dinner in her room better than she would in the dining room?" Mrs. Amarillo just nodded and smiled.

During another event of hygiene care, a CNA named Agatha left me alone in the

room with Ms. Horner while she prepared a wash basin for morning hygiene care. The

following field note excerpt demonstrates that Agatha knows how Ms. Horner will

respond to me, and also knows Ms. Horner's physical abilities.

Agatha came in and I said, "Ms. Horner is asking me to move her foot. She can't move her foot." Agatha said, "Oh, she's really playing you. She does that with any new person. She can move her whole body, but she likes to have everything done for her. Then when you do things for her, she says that it is hurting her."…She handed the washcloth to Ms. Horner and told her, "Okay, Ms. Horner, time to wash your face." So, she did wash her face with a washcloth. Then, Agatha prompted her to wash behind her ears, and she did wash behind her ears. Then Agatha dried her face and told Ms. Horner to lift her arms up, and she was able to do that. The CNA then cleaned her arm and under her armpits. I was surprised to see the resident moving her limbs so easily since she told me she could not move. Agatha said to me, "It is important to have the resident continue to do things for herself, because if she doesn't, she will lose all her abilities."

Knowing resident behaviors also facilitated CNA assessments of resident

conditions, providing information important to the plan of care. In this field note excerpt,

Wilma can tell that Ms. Peterson is in pain based on her behaviors during lunch.

Wilma came over to Ms. Peterson and called her by her first name and tapped her on the shoulder and said, "Carolina are you hungry?" Then she poured some soup in a cup and she said, "Drink some soup." As she is saying this she is holding the cup up to the resident's mouth. Ms. Peterson would not drink it from her, so Wilma handed her the

cup and she held it in her left hand but she was not drinking it herself. Wilma said, "The resident is in pain, that may be why she does not want to eat." I asked her how she can tell that the resident is in pain, and she said, "she normally would have more vocalizations and say no, no, no, but she is not saying anything today." The CNA also mentioned she can also tell by her facial expression which is sort of like a grimaced look.

"She Used to Work at the Post Office": Knowing the Resident as a Person

In knowing the resident as a person, CNAs describe what they know of aspects of their residents' lives prior to coming to CGC. These pieces of information are incorporated into the relationships with residents. Knowing the resident as a person also involves knowing social preferences and personality or character traits. This knowing begins to transcend the obvious initial purpose of the CNA-resident relationship, that of caregiver and care recipient. The CNA comes to know the resident as a person rather than just a care recipient, and subsequently use this knowing to shape interactions with the resident.

During an observation of hygiene care for Mrs. Peterson, Wilma's knowledge of Mrs. Peterson as a person helps her explain and rationalize the resident's behavior. Wilma interprets Ms. Peterson's actions based on what she has come to know and how she uses what she has come to know. She knows Ms. Peterson previously worked at the post office, and interprets that she is a strict lady and likes things a certain way.

The resident was sort of lifting her head off the pillow even though she was in a reclined position. The tendons in her neck were protruding possibly indicating she was straining to pick her head up as if she were trying to see something. Her head and neck were not relaxed. I asked Wilma if she does that a lot and Wilma said, "She does her own thing, she is a very strict lady. She will do this for a little while and then she will lie down." Then Wilma said, "You know she used to work at the post office, so she is a very strict lady."

In a subsequent interview, Wilma describes how she used to encourage Ms. Peterson to talk to her nieces on the phone. She also provides her impression of Ms. Peterson as a

sophisticated woman, based on her assessment that Ms. Peterson likes nice clothes and nice things. While she is drawing conclusions about the resident's persona, she is also working to maintain this persona for the resident as the resident nears death, as can be seen in subsequent excerpts.

She had nieces that used to call her and she would refuse the phone. She used to say no, no, no and I would say come on Carolina, talk to them and Carolina would laugh and say all right. The woman looked like she was a sophisticated woman. She had so much nice things, nice clothes.

Observations of CNA-resident interactions also revealed unidirectional verbal communication where the CNA talked to the resident in a personal way. These conversations were not about the care being provided, but rather about the resident's life events prior to living in the nursing home, the resident's family members, or the CNA's personal life. CNAs seemed to speak to residents about aspects of their own life as if they had a personal friendship with the resident. During an observation of feeding, one CNA was telling the resident about her daughter who was graduating from college, and how proud she was of her daughter, who was the first one in the family to graduate from college.

In the following excerpt, Wilma describes singing to Carolina Peterson and how much the resident enjoys it. She interprets the resident's enjoyment of music by her relaxed posture.

I used to sing. When I am taking care, I used to sing all the time. She loves music. You know, Carolina in the chair, when I see Carolina relaxing in the chair. Yeah, Carolina loves music. Always singing and always in the morning.

In the following excerpt, another CNA, Melissa, describes coming to know Mr. Lesser as a person. She said, "He was very stubborn. He just wanted his own way when he wanted something. He just did not want to compromise at all." She describes his personality and character traits as if she knew him personally. Interestingly, however, he had severe dementia during his entire time at CGC. Nonetheless, Melissa imbues him with characteristics that create a sense of a personality and not the effects of his disease.

In summary, as the early or concrete layers of knowing are revealed, CNAs cultivate an understanding of residents. CNAs learn likes and dislikes, and distinct behaviors, and use this knowledge in the care of residents. They also begin to know the resident as a person. This layer of knowing represents a transition in that knowing is becoming more interpretive and existential. They begin to draw conclusions about residents and construct personas for them, which subsequently influence their cultivation of relationships and their perspective on the meaning of their work. They are not creating an artificial person; rather, they draw together all of what they know in the hopes of understanding the person. This knowing the person is well intentioned and important, though it may seem to reach for characteristics of the resident not immediately visible to the casual observer. It permeates this Grounded Theory.

Cultivation of Relationships and Reciprocity

As knowing is cultivated, two additional sub-processes are unfolding. One is the interpersonal process of CNAs cultivating a personal relationship with residents, and the second is an intrapersonal process where the CNA achieves a gratifying relationship concerning his or her work. The process of cultivating knowing envelops and nurtures the growth of these relationships (see Figure 4). CNA relationships with residents begin

as assigned, and knowing serves mostly to facilitate the ability to complete necessary work. As knowing is cultivated, CNAs purposefully and deliberately strive for personal relationships with residents. As relationships deepen, interactions with residents clearly become more gratifying.

Implicit within these relational sub-processes is the concept of reciprocity. Reciprocity typically requires a mutual exchange whereby each participant gives and receives equally. Residents, however, lacked the cognitive and physical capacity to engage in such classically understood reciprocity. Rather, through the two relational sub-processes emerging within this Grounded Theory, the CNAs imbue residents with a relational capacity that allows for the possibility of reciprocity. This section describes the way in which CNAs cultivate personal relationships with residents, as well as achieve gratification in their work.

"It's Good When You Know The Resident": The Assigned Relationship

The CNA-resident relationship begins as CNAs are assigned to provide care for a resident. When CNAs meet residents, early knowing of resident likes, dislikes, and behaviors serves mostly to facilitate completion of assigned work. However, because CNAs aim to cultivate a personal relationship with residents, evidence of personal fulfillment is already emerging. The field note passages appearing in earlier sections depict how CNAs use knowing to make work easier, but also to provide care they feel is deserved by the resident. By knowing what Mrs. Schultz likes to eat, Ms. Verde feeds her quickly and easily, and also assures that the experience is pleasant for both of them. Additionally, she is concerned about the resident's calcium intake, and is pleased to meet that requirement. By knowing what Ms. Peterson likes to wear, Wilma avoids wasting

time and struggling with a fleece jacket after the resident is sitting up. She also prevents

Ms. Peterson from feeling cold, thereby ensuring her comfort.

"She's Playing You": The Social Relationship

Cultivating knowing resident behaviors and interpretation of these behaviors

fosters the cultivation of a social relationship. While the relationship remains the result

of a CNA-resident assignment within a professional context, CNAs begin to purposefully

develop social connections in an effort to cultivate a deeper relationship. Developing

social connections also facilitates perceived reciprocity in the relationship. The field note

excerpts that illuminate knowing resident behaviors are revisited in the following

paragraphs to illustrate this cultivation of a social relationship and reciprocity.

Ms. Amarillo discovered that Ms. Galveston would fatigue less quickly and eat a

more complete dinner if she were put back to bed prior to dinner time. Based on this

knowledge, Ms. Amarillo altered the care process of her entire resident assignment. With

the cultivation of this social relationship, Ms. Amarillo is delighted rather than burdened

by feeding Ms. Galveston in her room. She is able to give Ms. Galveston individual

attention and is simultaneously proud of her discovery.

As I observe Agatha provide hygiene care to Ms. Horner, Ms. Horner continually

says, "Miss Miss Miss." Agatha responds by saying, "Yes, Ms. Horner?" Which is met

with a response of, "Nothing." After several rounds of this dialogue I ask Agatha if the

resident does this routinely. She says yes and says it doesn't bother her, acknowledging

the obviously irritating perserveration. Agatha's deliberate cultivation of a social

relationship is thus seen in the way she engages with Ms. Horner. Agatha provides

simple instructions so that Ms. Horner can participate in her care, rather than doing

everything for the resident and treats a preservative habit of speech as conversation. Although having Ms. Horner actively participate takes longer, Agatha believes it is her responsibility to preserve any remaining physical capacity. Doing so gives her a sense of satisfaction. Finally, her interpretation that the resident is "playing me," by asking me to move her arms and legs, demonstrates Agatha's further interpretation of Ms. Horner's persona.

In the earlier excerpt, where Wilma is feeding Ms. Peterson lunch, Wilma's task is to get Ms. Peterson to eat, but she is not able to accomplish this. Social ties are evident as this event unfolds. Wilma calls the resident by her first name, provides verbal encouragement, and also rubs her back. She also interprets that the resident is in pain based on her behaviors. In a social relationship, if Ms. Peterson were able, she may verbalize that she is in pain and does not feel like eating. Over the course of this observation, Wilma tries to feed Ms. Peterson several other types of food, going out of her way to provide choices. Wilma ultimately concludes that she is tired and is not going to eat anything. She is visibly upset by the fact that she cannot feed the resident, nor make her more comfortable. Her expression of moral conscience reveals a perceived relationship that transcends that of caregiver-care recipient which is characteristic of an assigned relationship. Additionally, her emotional distress reveals development of an intrapersonal meaning of her relationship with Ms. Peterson.

In summary, evident within each of these scenarios of knowing resident behaviors is the beginning of gratification. As they learn, interpret, and act on resident behaviors, CNAs are moving towards achieving emotional satisfaction in their work. Ms. Amarillo nods and smiles as she reveals knowing Ms. Galveston's behavior, demonstrating pride.

Agatha feels it is her responsibility to preserve what remains of Ms. Horner's physical functioning. Finally, Wilma is emotionally distressed about her inability to neither nourish Ms. Peterson nor relieve her pain. This intrapersonal process further propels the cultivation of knowing and relationships to a personal level.

"She Loves When I Sing":   The Personal Relationship

Through coming to know the resident as a person, CNAs develop further social bonds and form deeper emotional ties with residents, culminating in a personal relationship. Through words and actions, CNAs portray relationships as one of a friend, confidant, and even family member. They draw on this knowing to bring purpose and meaning to their work, ultimately achieving a sense of gratification. The following examples demonstrate cultivation of a personal relationship and achievement of gratification through reciprocity.

As seen in the passage presented earlier, Wilma vividly portrays a deep sense of gratification when the resident responds so positively to singing. As she is describing this in the interview, Wilma is smiling with her eyes wide open. She describes her success in coaxing Ms. Peterson to talk to her nieces on the phone as if she were coaxing a friend to maintain connections with her family. Because of the personal relationship that Wilma cultivated with Ms. Peterson, Wilma seeks to maintain a sense of normalcy for Ms. Peterson. In the days before Ms. Peterson's death, Wilma expressed awareness of its imminence. Typically, when residents are confined to bed because of worsening illness, they wear a hospital gown rather than their customary clothing. Because of Wilma's personal relationship with Ms. Peterson, however, this usual practice was not acceptable to her. The following interview passage she explains her thought process.

She said, "Let me put on her dress because she would want to wear that. I did not want to see her in a gown. So I get her dressed. If she dies, she dies in her own clothes." At one point Wilma says, "When I give to Carolina, she receives," suggesting the underlying elements of reciprocity in the relationship. Furthermore, Wilma's tone of voice and body language indicated her pride in the depth of her relationship with Ms. Peterson, one that obviously gave her satisfaction and pleasure.

The personal relationship can become intimate in a manner than blends the professional context of physical care and with truly remarkable emotional meaning. Bonita cared for Mary Jimenez for many years, and developed a very close personal relationship with her. The following is an excerpt from her interview.

Mary is not on toileting but I saw that she was going (trying to move her bowels) and it was hard, so I thought that if I set her down for a little bit [on the toilet] it would come out. It did! I was so happy, you know? I was so happy!

Two days before the resident's death, Bonita was caring for Mrs. Jimenez and could see that she was having a difficult time moving her bowels on the bed pan. Although she is "not on toileting," which means she is not routinely taken to the bathroom, Bonita decides to take her to the toilet with the help of a coworker. When the resident was able to move her bowels on the toilet, Bonita was overjoyed. Her happiness as a result of this event underscores Bonita's achievement of gratification in her work. It also demonstrates the effect of the professional work environment on the development and maintenance of a personal relationship.

"Ms. Williams, It's Your Family"

CNAs care so deeply for residents that they often refer to them as family members. They describe relationships with the residents as "family relationships," portraying the depth of emotional connections often unsuspected in this professional context. . The description of family was used especially during emotionally difficult times, like the death of a resident. In an effort to portray the emotional loss of a resident, CNAs compare it to the loss of an immediate family member. In the following interview excerpt, Ms. Pasquale spoke generally about losing residents.

We get attached to them and we miss them. And it is like – kind of a family away from your family. Oh, God, we spend, I think the same amount of time we spend with our family, we spend with the resident.

In the following interview excerpt, Ms. Mendoza refers to her relationship with Ms. Williams as that of a mother and a daughter.

When I had her she had Alzheimer's so I just saw a different perspective….She never called me by my name, it was always "that person," but to her I was like her daughter, so that made me feel so special in that way.

Not only does Ms. Mendoza feel like she had a mother-daughter relationship with Ms. Williams, but she specifically states, "to her I was like her daughter," as if she is interpreting how Ms. Williams felt about her. In the personal relationship that Ms. Mendoza cultivated, she perceived that Ms. Williams related to her as if she were her daughter. This feeling of reciprocity is striking given the fact that the resident never called Ms. Mendoza by name. Ms. Mendoza's gratification is evident as she states, "that made me feel so special."

In another instance, Ms. Mendoza was providing hygiene care for Ms. Williams. Tim, another CNA on the floor, came in to help. The following field note excerpt reinforces the power of CNA references to residents as family.

Ms. Mendoza said to Ms. Williams, "I'm going to give you a good wash now." Then Tim came in to help her. She didn't really look like she needed help, it seemed more of a ceremonial gesture, since they both knew the resident would be dying soon. He said to the resident, "Come on, darling," and he held the resident's left hand. He touched her hand and said, "Ms. Williams, it's your family," trying to wake her up and rubbing her hand. They rolled the resident to her left side, and Tim was now holding her right hand on the rail and said, "Oh, look! She's still got it!" and he and Ms. Mendoza were both smiling at each other and seemed very excited. While she was holding on to the rail with her right hand pretty strongly, her left hand was still completely weak.

Both Tim and Ms. Mendoza clearly have a personal relationship with Mrs. Williams.

Interestingly, when Tim states, "Ms. Williams, it's your family," he speaks to the

collective family of staff and residents on his unit, including the three of them as family.

Both Tim and Ms. Mendoza are treating her with the respect and love that only family

members would express amongst themselves if a loved one were dying. In addition, Ms.

Mendoza's and Tim's happiness when the resident holds the side rail with her right hand

portrays the gratification they feel as a result of facilitating Ms. Williams' little remaining

independent function.

Bonita's relationship with Ms. Jimenez grew to become so personal and emotional

that she describes Ms. Jimenez as not only her grandmother, but also her children's

grandmother.

I was so attached to her. It was more than just patient care. I thought that she was actually like my grandma and my kids' grandma. We were like closely related. Every time she had a birthday we would celebrate, and we would come. My kids would come and have cake and all of that….. She met my kids. I met all of her kids and grandkids and great-grandkids. So it was like a family kind of thing, you know?

Her statement "it was more than just patient care" signals that in addition to providing

meticulous patient care, she also cultivated and maintained a personal relationship. She

also alludes to the reciprocity in the mutual social exchange during the celebration of

birthdays and other social activities.

CNAs do not actually choose the residents to whom they are assigned, and as a result they are as likely to enjoy working with the person as not. Yet, in all cases observed, the relationship was always obviously built on a foundation of respect. Even with residents whose personalities were less appealing or perhaps classically unlikable - for example stubborn, verbally abusive, or physically combative - CNAs still cultivate personal relationships. In the relationship Melissa cultivates with Mr. Lesser, she acknowledges that he is stubborn and never compromises. When she says, "He was always fighting us off, everything was a struggle," it is clear that his behavior makes it challenging for Melissa to care for him. Despite this, Melissa finds reciprocity in the relationship. At one point she says, "He let me shave him," underscoring her perception of the resident's active and willing participation. This is in contrast to the potential alternate phrase, "I shaved him," which does not connote reciprocity. Just prior to Mr. Lesser's death, Melissa states, "If we can make them look presentable even at the end, you know, it kind of makes you feel good. You know?" Feeling good about being able to make Mr. Lesser look presentable at the time of death, despite his inherently unpleasant personality traits, demonstrates Melissa's achievement of finding gratification in her work.

According to the CNAs who cared for him, Mr. Velasquez demonstrated behavior similar to that of Mr. Lesser, and he was verbally assaultive. In the following excerpt, Ms. Pasquale reflects on caring for Juan Velasquez.

Yeah, but still when you get used to them, you do not care how they curse you. You still –There is a connection, you know? … Really Juan was okay. I used to – you get used to him. I got used to him. …We was talking about it the other day because we miss Juan.

….Yeah, and then I get another new resident in his room today.…. So you get attached to them. If they are bad, you still get attached to them and if they are not bad they just come like inside over again. But you get attached to them. I miss them…. That is- what you call it- part of life, I guess.

Despite Mr. Velasquez's verbally caustic manner during almost every interaction, Ms. Pasquale still cultivated a personal and emotional relationship with him. Her reference to getting another resident in "his room" also illuminates the depth of the relationship. Although the rooms have numbers, to Ms. Pasquale this was "Juan's room." Her relationship to this new resident is assigned, the same way her relationship with Mr. Velasquez began, and has yet to develop the same depth.

In summary, implicit in the cultivation of knowing and relationships is the concept of reciprocity. Reciprocity connotes a mutual exchange, dependence, and influence in a relationship. At the outset, the CNA is focused on the resident and the relationship is largely unidirectional. Over time, as the CNA comes to know the resident as a person and develop emotional ties, the relationship becomes bi-directional or reciprocal. The relationship, then, is propelled to a personal level. In turn, they receive intense gratification from providing such care. The resident, however, is passive throughout this process. Apparently, aside from the occasional muttering of thank you or a smile, residents do not appear actively engaged in the relationship. However, CNAs utilize what they know about the residents as individuals and using it in the provision of often very intimate care. They foster the continuation of this knowledge by creating a persona, and developing emotional connection. Once a personal relationship is cultivated the impact of the relationship can be seen as residents decline and die.

Existential Knowing: Cultivating Meaning

As residents begin to decline toward death, subtle changes begin to occur. CNAs do not always know how to make sense of these changes, but frequently notice them and reflect on them. They have an emotional response to these changes, realizing they will lose the relationship so deliberately cultivated. Existential knowing is characterized by CNAs' recognition that a resident is nearing death. They detect subtle changes in resident behavior and eating patterns, but also have a general sense as a result of the carefully cultivated intensely personal relationship. CNAs also develop increasing knowledge, recognition, and sensitivity to impending death, due to their perpetual experience. Additionally, CNAs must manage personal relationships and loss in a professional context, leading to the conclusion that the job is not easy.

"She Was Not Kicking and Fighting Any More"

Detecting changes in behavior became quite significant as residents neared death. CNAs knew something was not right when a resident behaved in an atypical way or had a change in physical ability. While detecting these changes was significant, the changes were nevertheless very subtle, and CNAs had some difficulty articulating exactly what they observed happening to the residents, but understood the nearness of death. During an episode of hygiene care, I observed Wilma and Ms. Carolina Peterson. Wilma recognized that Ms. Peterson was declining, because she did not respond as she normally did to humor. The following is an excerpt from my field note.

Wilma says to the resident, "Carolina would you like me to get you a boyfriend? I am going to get you a good man, you need a good man." She kept on saying things like that and Wilma looked at me and said, "See she is not laughing, she used to laugh. This kind of conversation always made her laugh and now it is not making her laugh" ….Wilma said, "Oh this morning she said a little 'no' but she is talking much less. She used to have much more verbal ability and would say 'no' many more times than just once."

After Ms. Peterson died, Wilma continues to recall the resident's change in behavior. In

the following interview excerpt, she reiterates what she had said during the above event.

Yeah, she was going down. She was not kicking and fighting anymore. Her "no, no, no" was getting weaker and weaker. I know when she was tired when she was not making her noise in the morning. You see I am going, let me go in peace. Don't bother me. Don't bother me. So in me is like the feeling that she was saying that, you know, to herself. Because she is going, please stop bothering her. She is just tired and I think she gave up.

Ms. Pasquale describes knowing something was wrong with Mr. Velasquez,

because he is not behaving normally. At first, she has difficulty actually saying what the

changes were, simply noting that she could "see it in his face." She eventually notes that

the resident is less verbal and that he can no longer hold the hand rail during turning and

positioning. She is usually able to provide hygiene care for him by herself, but this time

she needed help from a coworker.

Ms. Pasquale: That was a difference. And I see it in his face different, the changes.
RT: And was he not – was he less vocal?
Ms. Pasquale: Oh yeah because he liked to curse.
RT: So that was a cue to you?
Ms. Pasquale: Yeah, that something he never – when Juan did not curse me today, you know that he was not the same.
RT: But his vital signs were okay, like he did not have shortness of breath? He did not have a fever and other things?
Ms. Pasquale: No.
RT: So from Friday the week before…
Ms. Pasquale: And the weekend we kept him in the bed over the weekend.
RT: Yeah. And then how about Monday?
Ms. Pasquale: Monday, oh, when I came about Monday I see the difference.
RT: Oh, really?
Ms. Pasquale: And I, me and another CNA help turn him and change him and then I said, he is going. He is not going to stay.
RT: Because normally he could hold onto the railing?
Ms. Pasquale: Yeah.

In the following excerpt, Karen describes detecting a subtle change in Mrs. Jimenez's

behavior.

Karen: She lie there, one thing I know, usually when I put her to bed, as soon as I get her

in the bed, she wants the pants off. She does not like- she wants everything off and just a gown on.

RT: Okay.

Karen: (this time)She did not complain.

RT: She did not say anything?

Karen: No. She did not say a word. I ran back, she had to take the pants off, she would scream and holler and scream.

RT: Say, take them off?

Karen: Take it off, take off the pants. Take off the clothes. (This time) she did not complain. I went back in there, when I went back there, she like to sleep on the left (side) comfortable. (This time) she turned the other way. She was just lying there.

.....

Karen: I came straight in here. I was talking to the girls in the evening and they did not say anything, we just were talking and then somebody came and said, then the nurse, what is her name, said to me, you see Mary? I said, no. Then after she said that to me, I went and run in there, she was on the opposite end (on her right side, not her left), she was not talking not responsive. Right away I knew.

RT: So as soon as you walked in the morning you thought she is going to pass away today?

Karen: Uh-huh….Then before I left I went back in there and looked at her and then I knew I was not going to see her when I came today. I knew she was going to, when I checked there, she was getting weaker and weaker.

.....

Karen: But for the few days, something was not right, she complained about pain but that was her norm, she was always complaining about pain.

RT: When she was quiet that is when you knew something was not right?

Karen: (nodding) She did not respond. Give me back the answer that she normally does. I said something is wrong, this is not Mary. Something is not right.

When Karen puts Mary Jimenez to bed, she typically demands to have her pants taken off immediately, and then turns to her left side to sleep. Karen knows this about Mrs. Jimenez after many years of caring for her. Changes in this pattern cause Karen to sense that something was not right. She does not want to acknowledge that Mrs. Jimenez may be dying soon, but based on her knowledge of and relationship with the resident, she realizes it is a strong possibility.

"She Did Not Want Anything to Eat"

Changes in the residents' typical eating patterns paralleled changes in behavior and physical ability. CNAs expressed worry when residents consumed less food, and

they often tried to do everything possible to encourage eating. Sometimes, however, the

resident ate more food than expected. This was perplexing to the CNAs because their

overall assessment based on changes in behavior and physical ability indicated that the

resident was declining. The sudden increase in eating caused confusion in their

assessment of the resident's status. Overall changes in eating, whether the resident ate

more or less than usual, were detected based on the CNAs' knowledge of the residents'

behaviors and patterns.

One day, as I followed Wilma as she was going to feed Ms. Peterson, she

lamented that the resident is not eating very much. In the field note excerpt below, she

tries very hard to feed her. Wilma even feeds her between meals, which is sometimes

difficult for her given her responsibility to care for the other residents.

I went in with the CNA and asked her how she feels the resident is doing and she said
'well this morning she only ate 25% of her breakfast and I really had to fight with her to
get the spoon into her mouth. She had some yogurt and some Ensure but that was
it….The CNA told me that between meals she tries to give the resident a little bit more
Ensure and a little bit more yogurt just to try to get her to have a little intake throughout
the day.

Melissa cared for Mr. Lesser throughout his time at Community Geriatric Center. He

eventually stopped eating, and she believes he made a conscious decision to stop eating

because he did not want to live any longer.

Melissa: Since Thursday he refused to eat. So I tried with the Ensure and you know, he
just didn't want to. So the nurse said you know why she called his family and they said
you know two people were trying.
RT: And they didn't want him to the hospital or anything?
Melissa: No. You know. They didn't want to give him a feeding tube. They wanted to
just let him go in peace.
RT: Yeah. He probably would have fought it and pulled it and all kinds of things. Do
you think?
Melissa: Yeah. Yeah. ....You know, if he decides. I believe he had made a decision,
you know? Because he actually stopped eating. So it's not like he got ill and he

actually…
RT: He couldn't eat. Yeah.
Melissa: Right, couldn't eat. He just decided he was not going to eat.

Karen, a CNA who cared for Mrs. Jimenez, had a feeling she was going to die soon,

because she did not eat. This sense strengthened for Karen when Mrs. Jimenez also

refused the things that she typically loved the most.

RT: Were you there the day before (she died)?
Karen: Yes.
RT: Saturday, what was she like that Saturday?
Karen: She was quiet but I noticed she did not eat, she did not want anything to eat.
RT: On Saturday?
Karen: Yes.
RT: Did you think something was going to happen?
Karen: I had a feeling.   She refused when I gave her the breakfast. I gave her breakfast,
she refused again....But then I got her up I got her up late and I dressed her and I said to
her okay you are going to eat a little bit and then I will put you back. So I brought her in
here and she did not want to eat, she did not want nothing. Even tea that she loves, she
loved tea. I make the tea, ice cream, whatever she loves, she did not want, she did not
touch nothing.

Ms. Mendoza recalls Ms. Williams eating more than she expected, and then

dying. Although she knew the resident was going to die soon, Ms. Williams' sudden

increase in eating gave Ms. Mendoza hope that she would remain alive a little longer.

Loss of the relationship came too quickly for Ms. Mendoza. She said, "I think it was too

fast for me. I don't know, because you see, the one day before she ate everything**."**

In the following excerpt, Ms. Pasquale, a CNA who sometimes cared for Juan

Velasquez in the evening, recalled the resident eating a lot, which was inconsistent with

her overall assessment of his condition. Mr. Velasquez was being fed in bed because his

posture became so hunched and he was so weak that he could no longer physically

tolerate sitting in the wheelchair.

Ms. Pasquale: And so when I talked to him I said, "Juan, what happened to you?" But

you could see that he was deteriorating. So that evening – was very difficult to feed. And for the weekend we kept him in the bed. But see, he ate everything!

RT: It was harder, but he still ate it?

Ms. Pasquale: He ate it, yeah. And when he is in the bed now he lie down and I could get to his face more and – but you could see that he was not the same.

In summary, detecting changes in resident behaviors and eating patterns led CNAs to the knowledge of approaching death. As CNAs were faced with this existential knowing, they reflected on how it affected them personally, and how the cultivation of a personal relationship and gratification in their work affects their job.

"This Job is Not Easy"

Time and time again, CNAs emphasized that their job is not easy, though it may appear to rote and rather mechanical to a casual observer. They pointed toward many different aspects of their jobs that were hard for them to bear. Most obviously, providing personal care for multiple people every day is physically demanding. Ms. Verde said, "You know, this job is not easy. I just provide everyone with the best care that I can." On one of the units, the residents have severe dementia, but are still ambulatory. This is a uniquely challenging group of people for whom to care. Ms. Pasquale, one of the CNAs on that unit, emphasized a collective effort among her coworkers to provide residents with needed care although it is often overwhelming. She said, "On this floor is not easy. It is difficult. It may look easy, but it is not. But all of us work together and help each other. Otherwise we never finish. That is the way we have to do it."

In addition to the physically demanding nature of the job, some structural aspects the nursing home environment make it difficult for CNAs to act on knowing as a way to provide care they believe to be needed and deserved. A classic example that surfaced several times during bathing events was the application of body lotion. Community

Geriatric Center previously supplied tubes of body lotion, so that the CNAs could have it

readily available for skin care. Now, however, lotion is kept in the residents' bathrooms

in a dispenser attached to the wall. The new location and packaging require the CNAs to

leave the bedside, walk into the bathroom, collect as much lotion as possible, and return

to the bedside. CNAs must provide hygiene care to approximately eight residents during

a shift, so it is easy to see that CNAs may forego the application of lotion. While the

CNAs I observed expressed frustration with the process, they did not consider the option

of not applying lotion. They understood the impact of thin dry skin on residents' well-

being and comfort. The following is an excerpt from a field note describing this process:

The CNA went into the bathroom and got the lotion out of the pump, which seems to be
the common occurrence, and put it on the resident's arms and chest. I asked the CNA
about this lotion process, and she said that it is more difficult for her because if she had
the lotion right there in a bottle, she could use it much more easily, but now she has to go
and squirt it on her hand and bring it back. She said that the resident really needs it, so
that is why she continues to use it on her…..She went back into the bathroom again to get
more lotion on her hand and she turned and said to me, "See, you have to go back and
forth, back and forth," which I would expect the CNAs would eventually just not do so
much, but they still seem to keep up this routine even though it is more burdensome for
them.

Interestingly, however, the physical demands and structural barriers were not the

focus of difficulty the CNAs described. Rather, the emotional burden of losing residents

whom they loved stood out as the crux of their challenge. CNAs describe the personal

relationships that develop with the residents, and that their work consists of more than a

series of tasks. CNAs are profoundly aware that caring for human beings who cannot

care for themselves is a unique responsibility. Emotional bonds are formed with

residents leading to friendships, and CNAs suffer emotional losses when residents die.

Tim noted, "It's hard to let go of any of the residents that you have from over the

years…but you just have to learn how to adjust…real quick." In an interview, he described how he would coax Mr. Folsom to complete his hygiene care. When Mr. Folsom got distracted and wouldn't cooperate, Tim would coax him by saying, "I thought we were friends." When he said this, Mr. Folsom would comply. As Tim reflects on learning of Mr. Folsom's death, he said, "I was like wow, no more, 'I thought we were friends', no more of that."

Because of the carefully cultivated relationship fostered by CNAs, they are often overwhelmed balancing the personal ties with professional responsibilities. When residents die, CNAs experience a profound emotional loss. The following excerpt from an interview with Melissa portrays how she and her coworkers become very attached to their residents, and the emotional responses they experience when residents die.

You know, we become very attached. You know, a lot of people I guess believe that this is just a job, and even sometimes the work is hard and you feel overwhelmed….It's not a routine job to watch them pass and transfer them to the morgue. You know a lot of times we're crying all the way out.

In the following excerpt, Melissa describes the complexity of balancing her professional responsibilities and her emotional connection to residents. She uses the analogy of a family member to portray the depth of the emotional attachments. She speaks as she is packing Mr. Lesser's personal belongings.

This is not just a number or room. This is somebody that lives here. You know, and this somebody you are responsible to take care of them and you're responsible to give them the best possible care that you can. You know? Because you know you would want somebody to do this for your family member. Just the fact that you're here and you have a heart and you met them and you became friends with them and you know them, it's like this person becomes a part of you somehow. Even though this is not your family member, but they actually become a part of you and when they do pass on it's really painful. A lot of people don't realize that, but it is.

Acknowledging Impending Loss

"I Like to Treat Them Special and Give Them Extra"

CNAs are significantly affected by the impending loss of their relationships.

They realize that they cannot prevent death from happening, but can still positively affect

the resident's daily life through meticulous care and attention. The work of the CNA

may appear to be straightforward and routine. To the casual observer it can appear as if

they apply an "assembly line" mentality to resident care. Upon close examination,

however, evidence of steadfast care and attention shows how much CNAs care about the

residents. They express pride and satisfaction in their work especially by noting the

personal care for each resident, and alteration of routines to assure optimal care. CNAs

also purchase hygiene and personal care supplies for residents in order to maintain a

standard commensurate for the individual with whom they now have a meaningful

relationship.

In the following excerpt, Wilma describes her rationale for bathing Ms. Peterson

in bed, rather than providing a shower.

I used to give her a shower, but I stopped because I do not want her to have pneumonia, so that is why, when I start, I clean her up in the bed. We did not want to put her in a shower anymore…. I am going to leave her in the bed. I am not going to bother her to have her sitting up in the [shower] chair because she is in pain. So I leave her in bed and come check her out in the bed. I washed her and even-she gets more clean, you get more clean when you are in the bed. I can clean her more properly, and I changed all the linen.

Wilma can see that Ms. Peterson is getting weaker, and she is concerned that a

shower will do more harm than good, offering a clinically unfounded interpretation that a

shower could cause pneumonia. Wilma also believes she can bathe the resident more

thoroughly in bed and provide greater comfort. Her concern for the resident's welfare is

evident in her rationale for providing a bed bath rather than a shower.

The following is an excerpt from a field note where I observed Gladys, a CNA,

providing hygiene care to Ms. Latham.

Then, Gladys took the basin and went into the bathroom and came back with a fresh basin of water. She said that when you do the bottom half of the body, you need to change the water. The other water was dirty and that would spread germs. She did not actually say the word "germs", but she just said it would not be good to use the same type of water. She started to clean the resident's private area. She squeezed a lot of water out from the washcloth, and Ms. Latham said, "Don't wet the bed!" I guess the resident was paying attention even though Gladys was not really talking to her during this time. Gladys said to her, "Don't worry. I'm going to change it." Then she said, "I'm going to turn you," so the resident actually began to reach with her hand over to the side and started to turn herself a little bit. Gladys started to wipe the resident's backside, and she told me that she did change this resident first thing in the morning, because now it is about 12 noon, and their shift started at 7:30 a.m. So, she changed her already in the morning, and when she wiped the resident now, she showed me the washcloth and smiled and said, "See, she's still clean!" She also said, "You have to treat everyone the way you would treat yourself." She provides hygiene care for this resident, at least the perineal area, two times during her shift.

Gladys' statement, "you have to treat everyone the way you would treat yourself," speaks

to the collective respect CNAs have for residents. Rather than using one basin of water

for the entire bath, she changed the water half way through the procedure. The CNA

applies the same standard of care for the resident that she would want for herself. She is

also proud of the fact that Ms. Latham's perineal area is still clean from morning care.

Ms. Wynona Kennedy had been very ill with pneumonia for over two weeks. Her

primary day CNA, Lourdes, was happy to see that Ms. Kennedy was more alert than

usual one particular day. The following is an excerpt from my field note of the event.

I asked Lourdes if this was Ms. Kennedy's regular shower day or if she was just "snuck in." Lourdes said, "Oh, I snuck her in because I saw that she was looking good and I wanted to give her a shower." After the shower……Lourdes went out to the paper bag in the dressing area and got out a tube of lotion that was Bath and Body Works brand, and began to use it liberally on the resident's arms, legs, and back. In an effort to cross-reference my previous observations about the use of lotion, I asked her if Community provides lotion and she said yes, but "The stuff they have here-by tomorrow it will smell like she didn't take a shower." I asked her if she brought all these supplies in the bag and she said, "Yes you have to bring your own stuff-you have to." I asked if her co-workers

do this as well, and she said "Yes, everybody does." Next she combed the resident's hair and put some styling gel in it. She said, "This will hold her curls." Last, she put Vaseline from her own tub on the resident's lips. Then she stepped back from the resident, looked intently at her face, and smiled. The resident was smiling too. Lourdes appeared to be happy with her decision to shower the resident and get her fixed up.

Although it was not her designated shower day, Lourdes decided to give Ms. Kennedy a good shower because she hadn't had one in almost three weeks. She diverges from her usual schedule by "sneaking" Ms. Kennedy into the shower schedule, disrupting her day and also that of her co-workers all for the sake of a fastidiously completed shower. She makes the experience even more personal by using her own bath products. She believes using these supplies will maintain Ms. Kennedy's hygiene at a standard the resident would probably have done herself if she were able. Lourdes finds this encounter with her resident gratifying, as evidenced by her satisfied facial expression as she looks intently at Ms. Kennedy.

The next excerpt is from a field note where I followed Ms. Amarillo into Ms. Galveston's room as she was preparing to get the resident ready for bed.

The CNA wheeled the resident into her room in the wheelchair and she took out a key from her pocket and opened up the resident's top drawer and there were a whole bunch of toiletry supplies in that drawer. She told me this is where she keeps all of the supplies that she uses for her residents. So this is within a resident's room, in the resident's dresser, but the CNA has the top drawer with a lock on it that she keeps her things. She showed me all of the things that she has in there, motioning with her hand for me to look in the drawer. She has Act mouthwash, Secret deodorant, and she has some other kind of body sprays from Bath and Body Works that are different scents. These are all brand-name products, not inexpensive things you can buy at the dollar store. She has Vaseline and some other kind of lotions and some containers of air sanitizer spray, all different scents. She said that she buys them for the residents because the supplies that are given by Community are okay, but she said, "I like to spend a few extra dollars for my residents. I like to treat them special and give them extra."

Again, the use of personal bath products underscores the CNAs' attention to the personal relationship and preservation of the residents' personas. At the end of the event, Ms.

Amarillo said, "They all have illnesses and they all deserve to be treated good." Then she kind of laughed and smiled and said, "and smell good." After saying this, she took out one of the scented sprays and sprayed it in the air over the resident.

Evident within each of these scenarios is the CNAs careful attention to what they perceive would make the resident most comfortable and happy. By "giving extra," they exemplify their love for the residents. They believe they know what the residents would want and also know how to attain these standards. They use their own supplies to maintain a personal standard they believe the residents would maintain themselves if they were able. They believe this is what the residents "deserve" and feel a sense of satisfaction in being able to facilitate such care. Ultimately, the private and personal interactions described here portray CNAs cultivating existential knowing and meaning in the relationships as their residents near death.

<center>*"Bye Henry, I'll See You Monday"*</center>

When CNAs know that death is imminent, they say goodbye to their residents. Having the opportunity to say goodbye to a resident prior to his or her death is a profoundly meaningful activity in that it helps make sense of the loss of the relationship. Explicitly acknowledging that the relationship is coming to an end demonstrates CNAs' honor and respect for residents. Furthermore, through a carefully constructed sense of reciprocity and perceived relational capacity, CNAs believe residents participate in the goodbye. Through existential knowing, CNAs describe having a feeling that the resident is going to die soon, and do not want to miss the opportunity to say goodbye.

In the following excerpt, Melissa, Henry Lesser's primary CNA, says goodbye to him because she realizes that this may be the last time she sees him.

Well, I don't tell him goodbye like I'm never going to see him again. But in my heart, I had a feeling I wasn't going to see him again. "Bye Henry, I'm off this weekend. I'll see you on Monday. I hope I'll see you on Monday," you know? I said, "Bye Henry. Tell me bye Henry." He was there, you know, and he's trying to get the oxygen off and I'm trying to distract him. "Tell me bye Henry. Bye, I'm going. I'm going to see you on Monday, Henry okay?"

Melissa acts as if she will see Henry again, but knows that she likely will not.

Additionally, Melissa's perceived reciprocity is evident as she encourages Mr. Lesser to

say goodbye back to her. By doing this, she is also attempting to emotionally protect him

from knowing about his own impending death.

In the following scenario, Tim, the primary evening shift CNA for Juan

Velasquez recalls saying goodbye to the resident. He describes a short yet very personal

and intimate conversation with Mr. Velasquez.

I said goodbye to him over the weekend. I kinda had that feeling. You know, I said, you know, Juan, that's all, we sat there and I talked with him for a little while and I said goodbye right then and it happened on my day off. So….I could feel it. I said, "Whoa, Juan, you know, you don't have long."

Tim's choice of words, "I talked with him" reveals the perceived bidirectional nature of

the conversation, and underscores Tim's belief in reciprocity in the relationship when he

states "we sat there."

Prayer emerged as another avenue from which goodbyes are said. Prayers and

spiritual references extend direct goodbyes, however, in that they also indicate CNAs

letting go of the residents to a spiritual realm. Both Melissa and Ms. Bellamy cared for

Mr. Lesser just prior to his death. Melissa struggles with the impending loss of her

resident. She is distressed to learn that Mr. Lesser is not doing well, so she tells him that

God has not given him permission to die. She also feels that he responded to her

statement by her assessment of his physical movements.

Melissa: I was talking to the nurse you know? She said he's starting to get bad. So I was telling him Henry, God hasn't given you permission yet to go. You know? You can give up but you have to wait for God to give you permission and I don't think he gave you permission yet Henry. You know?
RT: Was he responding at all to that?
Melissa: Yeah. Yeah. He was not really verbal, but he twisted and turned. You know, like, you could tell that he was listening.

Ms. Bellamy is another CNA who cared for Mr. Lesser in the evening. She also spoke in

spiritual terms about recognizing his impending death.

I know he's ready to go. Okay? I said, "Okay maybe the time is ready for you to go. I expect you to go with your God. If you believe in Him, in God, so I expect you to go in Heaven. Okay? And have a good trip. The time is coming. May God be with you."

In summary, CNAs go above and beyond what is expected of them as they strive

to make the residents as comfortable as possible and maintain the personas until death.

This is exemplified by the importance they place on acknowledging impending death and

saying goodbye. Interestingly, CNAs create these relationships with residents who have

very little if any capacity to interact. With a firm personal relationship, these acts help

CNAs cultivate meaning as they come to the end of the relationship.

Culmination of Knowing and Relationships

"He Needs Somebody Beside Him"

CNAs at Community Geriatric Center provide compelling stories of their

experiences with residents near the time of death. They describe it as a privilege, and are

honored to be present as residents near death. None of them express any negative

reactions such as fear, disgust, or aversion to being present. Ms. Bellamy, a CNA who

sensed that Mr. Lesser was going to die said, "Once somebody's going this way, you

need somebody beside him, right?" She would not have even considered leaving the

resident to die alone. She felt it was her duty to stay with the resident. Another CNA,

Sally Rae, described sitting with Ms. Williams when her death was imminent. She

expressed that she would do this for any resident who was in need of companionship,

because she felt a special connection with all residents.

Sally Rae: when she was crossing over to the other side, John (the resident's grandson) had called and asked us not to leave her alone, and I said, "You don't have to call and ask us that." I sat with her one afternoon and I was talking with her so I told her if she could hear me and understand me to squeeze my hand I said to her, "Margaret, this is Sally Rae, if you could hear me and understand me, squeeze my hand." and she did, so, she knew she was not alone. If anything they always know your voice, they always know your voice.
RT: So you chose to spend your lunch hour in her room even though you did not have to do that?
Sally Rae: No. I chose to, I chose to.
RT: Because you have a special connection with her?
Sally Rae: All of them really. Yeah with all of them. Some closer than others, but with all of them.
RT: So if anyone had needed that kind of closeness you would do it?
Sally Rae: Oh yeah, yeah.

When I asked CNAs what they did specifically as residents were dying, several of

them noted holding the resident's hand, or having their hands on the resident in some

way. Julia said, "I rubbed her hair. I rubbed her hand and I was talking to her," when she

described caring for Mrs. Orfanos just prior to her death. Ms. Bellamy described her

experience holding Mr. Lesser's hand as he neared death. She sensed that he was lonely

and in need of a human connection.

No one was there to hold his hand. That's why I hold his hand. I hold his hand. The way he hold my hand, he makes me feel that he is lonely. He was lonely. Once somebody's going this way, you need somebody beside him. Right? Even though you write something down, like when I'm going to go don't give me this or don't give me this (referring to advance directives or living will), but this is a human being right? He needs love. He needs, you know, comfort or something like that.

The description of holding hands was consistent with several events I witnessed where CNAs touched residents in ways that communicated love and tenderness. The gesture of touching the resident during death demonstrates CNAs' humanity. CNAs' desire to maintain a human connection for the residents, even though the residents themselves were likely unaware of it, was profound.

Once Melissa, Mr. Lesser's CNA realized that he would likely die soon, she became very distressed at his appearance. His beard was thick and he had crusts around his eyes and mouth. She was concerned that he would die looking that way and wanted to preserve his personhood and dignity through death, both for himself and his family. Because of his combativeness, however, she could not provide the care that she felt he needed. She seized the opportunity when he was very near death and not fighting as much as he normally did.

Yeah, he didn't want you to touch, he didn't want. You know we were trying to put the oxygen on him and he was waving his hands in front of us so that we couldn't put the oxygen. He didn't want us to actually, you know clean him up. But you know you just can't leave him in that state. I wanted to give him a shave before the weekend because I was going to be off this weekend. He just didn't look that well. So you know, the beard started growing in kind of thick. I said, you know what? He didn't fight as strong. He wasn't breathing that well. So I said, you know what? This is the perfect time to get a shave. I lathered him up and everything. You know, I shaved him. You know, he didn't put up much of a fight but he pretty much was still fighting. But I didn't want to leave his face like that….I didn't want him to go looking like that. You know. I didn't want- his family were going to view him…. After a shave he actually looked well. You know? So it's a big difference you know. It's like kind of hard to explain, but it's like your parent. You know you wouldn't want to see your parent looking like that at the very end. So I wouldn't want anyone to have to view their parents looking like that. You know? So if we can make them look presentable even at the end, you know, it kind of makes you feel good. You know? After the shave, and you know, we cleaned him up really well because, you know, he had started fighting everyone to wash his eyes and his mouth. I got it all off (gesturing to the crust he had around his mouth and in the corners of his eyes). So he looked like Henry, you know?

Sally Rae was one of the CNAs caring for Mrs. Williams when she died. She

describes a similar scenario where she and her co-workers worked to ensure Mrs.

Williams had appropriate clothing at the time of her death and for her funeral.

Sally Rae: The CNAs, the social worker who works here, we went and got her clothes from, we have, we call it Macy's, so we went and got her a little outfit to put on her.
RT: Oh when she passed
Sally Rae: We got clothes to bury her in.
RT: Oh you chose them yourself?
Sally Rae: No, no, another CNA and someone else went down and picked some clothes out for her then we all laid the clothes out and we all decided and [the community director] we decided what would be the nice outfit.
RT: This is on the day she passed away?
Sally Rae: The day after. We got clothes. He [John] wanted us to put something on her, but we did not feel that the clothes that she had in her closet were appropriate. We went down to Macy's, Community's Macy's (referring to a room where extra clothes for residents are kept), and we picked some clothes out for her. We had a few outfits, we brought them upstairs, and we all agreed to put the white outfit on her.

The following passage epitomizes the profound love and respect CNAs have for

their residents. This passage is part of an interview with Wilma, the primary CNA for

Ms. Peterson. She describes the way in which she cares for Ms. Peterson in the days

leading up to her death. Specifically, she describes the importance of the resident

wearing her own clothes rather than a hospital gown, as alluded to earlier. Wilma's

actions are similar to those of Sally Mae noted above. She describes this as her typical

practice for her residents.

Wilma: Yes, I put on her dress. In the morning, every morning I am looking [in the closet] for [a nice dress for] her because I know she is going soon, so I say, put a gown on her? And then I dress her up every morning [in her own dress]. And change her bed, change her bed every morning. So she's clean and she have on her dress, and everything, you know?
RT: Sometimes I see when residents are getting sicker, and they are staying in their room and they are not coming out anymore, that they are in a nightgown like the hospital gown.
Wilma: Why do you want to put a gown on her? I said let me put on her dress that she would want to wear that. I did not want to see her in a gown. So I get her dressed. If she dies, she dies in her own clothes. And when she died, I changed her dress and put on the

gown, put her in the bag, you know? Tie her up and I take her down to the morgue. I put her in the fridge and I say, "Bye Carolina."

RT: Oh. So, they did not really have to do too much postmortem care, because I guess you had cleaned her so well.

Wilma: No, I cleaned her up and everything. They do not have to do anything for her. I put the dress for them to put on her when she get buried.

RT: Oh, you chose the dress for her?

Wilma: Yes, what I say I take her dress and put it in a bag and put it inside the fridge with her. Because she has no family, you know? You don't want her to be buried in a gown. They're not going to have a dress [at the city morgue] so I put her dress on her.

RT: Oh, wow, that was nice thinking of you. So you thought of that on your own?

Wilma: Yeah, we know when they die and we see nobody then we have to put their dress back on. You do not want them to be buried in the gown. If they have clothes, why should they be buried in the gown? No, we put on the dress. You know, Mrs. White (another resident) used to have so many dresses, and when she died, I bring a dress for her too; put the dress in there for her. She did not have any family. She was such a nice lady.

These passages illuminate the extraordinary measures CNAs take to preserve residents' personhood, and ultimately their dignity, through death. Their actions are commensurate with those of family members or loved ones, not traditionally expected of paid caregivers. The CNAs descriptions of what they did as the residents died; their comments on how providing such care made them feel; and their tone of voice and facial expressions indicate they have achieved gratification. Even at the time of death, the CNAs are concerned with how the residents will be presented at their next place, wherever that place may be.

CNAs desperately want to be with their residents at the time of death. When CNAs were not with their residents at the time of death, they express sadness and lament. In the following two cases, the CNAs were not present with the residents, but wished they were. Upon learning of the deaths, they went to the residents' bedsides immediately. Wilma was providing hygiene care to Ms. Peterson, her resident of many years. She felt that the resident was going to die that day. She wanted to stay with the

resident, but had to leave the room to take care of other residents. Ms. Peterson died

while she was in another room, and her co-worker found her to tell her the resident died.

Wilma was upset that she was not there, and asked her co-worker why she did not get her

right away. In the following excerpt, an intimate bond between CNA and resident can be

felt.

I clean her, I polish her and I cover her and I say I will come up and check on you. As I
am leaving her, I want to go back. I couldn't stand it because I know she is going to leave
as soon as I leave the room, I know she going to go. So I leave the room. I go back on
[another resident] and clean him up and I say okay, let's go back and check on her, [she
says to another CNA]. By the time I get here, I am going up to the room to put some
linen, [another CNA] told me she just passed, that Carolina just passed. I said, "Oh, my
God, couldn't you call me and tell me when she was going?" She said, "No, there wasn't
any time." Then that they prayed for her and they hold her hand. Pray for her. And I said,
"Carolina, Carolina, you gone you gone now." I say, "Rest in peace," and I say "oh, she
suffered a lot." So much pain the lady was going through. She was going through a lot of
pain and do you know, I feel sorry for her. Nobody comes to see her. And so I feel very
sad for her. She knows I used to love her, though, you know, and she knows that.

Another CNA, Bonita, was called by her coworkers on her day off when her long

time resident Mary Jimenez died. She describes the bond she developed with this

resident over the years as that of being related. Bonita had her children during the years

that she cared for Mrs. Jimenez, and when she realized the resident was declining, she

wanted to take her children to see her. Bonita had such a personal relationship with Mrs.

Jimenez that she came to the nursing home with her daughter on her day off to say

goodbye. In this interview, I asked Bonita to describe how she learned of Mrs. Jimenez's

death. She references feeling like the resident's granddaughter.

RT: So you were home on Sunday but someone called you?
Bonita: Yes. A friend and a coworker called me. I was just getting ready to go on a
picnic that beautiful Sunday afternoon, you know? I just could not believe it, you know?
RT: So how was it on Monday when you, you came on Monday?
Bonita: I actually came last Sunday like 45 minutes after she passed.
RT: So you came. What made you come on Sunday?

Bonita: I do not know. I was so attached to her. It was more than just patient care. I thought that she was actually like my grandma and my kids' grandma. We were like closely related. Every time she had a birthday we would celebrate, and we would come. My kids would come and have cake and all of that.

RT: When you were on your way here on Sunday, what were you expecting? Did you have any thoughts about what you would see?

Bonita: I could not believe that she was actually going. Her daughter was saying that she would not raise her arm. She was not answering-and just how she was breathing. I thought to myself oh that pacemaker and that oxygen was keeping her alive. Yes, I couldn't believe that 6:15, that is when she passed away.

RT: So were you here at that time?

Bonita: No, I came 45 minutes later at seven o'clock. I was here at seven.

RT: Okay. What happened when you came?

Bonita: When I came I saw her and I could not believe she was gone. She looked like she was sleeping. She was still in bed. I actually brought my daughter in to see her for the last time. I had promised her that I would bring her to see Mary, but time came short on me. Then I had no choice but to bring her the kids. She overheard everything and she said, mom you know you said you were going to take me.

When I was speaking with Claudia, a CNA, about Ms. William's death, she spoke generally about receiving notification that a resident has died. It seems to be common practice that co-workers call their colleagues who are not at work to immediately inform them of a resident's death. She explains that losing a resident is emotionally upsetting. Her final statement supports the notion that the CNA job is emotionally intense.

I got a couple of phone calls last night letting me know that another one expired. I mean just hearing it, you can tell that they were upset, you can tell that they were sad. This is a part of your life, seven days, for eight hours, so yes, it is kind of hard, you know you internalize a lot, people take it for granted that we do not have any feelings about it, but we really do.

"Say Goodbye One Last Time"

Post-mortem care is the time-honored activity of preparing the body to be transferred to the morgue. It is done immediately upon the resident's death usually by CNAs, but sometimes also by nurses. Post-mortem care can often be a very task-oriented activity, especially when a relationship does not exist between the care provider and the

resident. Two excerpts from residents' medical records support the common

misconception that post-mortem care lacks emotion or compassion.

At 12:30 post mortem care given and transferred body to morgue. Family donated all belongings to CGC. Admissions informed.

Doctor came to floor and checked resident. She spoke with wife and informed her of resident's expiration. Postmortem care done and sent body to morgue. At 2:00 p.m., personal belongings are for donation as per wife's instructions. On 7/25/09 at 1:00 p.m., body was removed to the funeral home.

In this Grounded Theory, CNAs' descriptions of post-mortem care reveal a deeper

meaning and purpose than simply wrapping the body and applying the appropriate

identification tags in the appropriate places. The CNAs seem to feel honored and

privileged to provide post-mortem care for their residents. Post-mortem care typically

requires only one or two people. In several instances, however, it is provided by several

people who have cultivated personal relationships with the residents and care deeply for

them. Their presence is not required, but they are present both for their colleagues and

out of respect for the resident. It is an opportunity to say goodbye one last time.

When Mr. Folsom died, Tim, his primary CNA from the seventh floor, described

providing post-mortem care. Even though Mr. Folsom died on the tenth floor, Tim and

his co-workers went up to the tenth floor to provide post-mortem care in conjunction with

the tenth floor staff. Tim felt it was important that Mr. Folsom's post-mortem care be

provided by those who knew and loved him. This gesture preserved Mr. Folsom's

identity in death, and also provided an opportunity for the seventh floor staff to say

goodbye to him and be with him one last time. The opportunity to escort Mr. Folsom to

the morgue was symbolic for Tim. The following is an excerpt from Tim's interview.

Tim: So then one of the workers upstairs knows [Mr. Folsom was] one of my residents. She called and said look make sure House Seven knows that he passed. So, well she called, they called, the nurse called and told us, and we came up. Our workers, the nurse, and we all went upstairs and said good bye to him. And I stayed and my co workers stayed to help wrap him up so we wrapped him up and….

RT: So it was your staff, you and your co workers?

Tim: Me and my co workers and their co workers, the co-workers upstairs. So we wrapped him up got him ready. And uh took him downstairs, I took him downstairs to the morgue.

RT: But to be able to, you know, provide his post mortem care… and how did it?

Tim: That just, that's great you know? Get to say good bye one last time. You know I was on vacation when he had went to the hospital.

Melissa described providing post-mortem care for her residents with whom she has cultivated a personal relationship. She said, "It's way beyond the job, because if it was the job it would be routine. I have to do this, this, this, and this. And then I wrap the body, take it downstairs, it's over. It's not like that."

Bonita stated that she helped provide Mrs. Jimenez's post-mortem care, even though she was not officially working at the time of the resident's death. As seen in the earlier excerpt, she came in on her day off with her young daughter to say goodbye to Mrs. Jimenez after learning of her death. Bonita felt it was appropriate to participate given she had such a deep and personal relationship with the resident. She also attended the resident's funeral. In the following interview excerpt, she describes her feelings about saying goodbye to Ms. Jimenez for the last time.

Well, at the moment that I was there; I was feeling like so much emotion coming to me now. Like she left me, I felt like she left. And she did not see me accomplish my schooling. I felt that and then I got hurt and I cried. Yes, and then when I left, I felt you are missing something, you know, like it was the last goodbye, that I would never see her again. I felt strange. But I was happy that I went, of course. I needed to go.

Bonita's experience of attending Mrs. Jimenez' funeral solidifies the reciprocity inherent in their relationship. She feels that when the resident died, she left her. She reflects the

death personally as if Mrs. Jimenez intentionally did something to her. Her disappointment that Mrs. Jimenez would not see her graduate from school stresses the personal nature of their relationship.

In summary, the CNAs describe post-mortem care as a rite of passage, a symbolic event in their relationships with the residents. Bonita's experience in attending Mrs. Jimenez' funeral has similar undertones. Overall, the events surrounding the residents' deaths demonstrate CNAs desire to provide humanistic and compassionate care. Medicalization of the residents' deaths was noticeably absent. CNAs did not describe any panic or rush to institute medical intervention. Nor did they discuss the event as medical in nature. Rather, death was accepted by all involved, and facilitated with respect for the individual residents.

Summary

This emergent mode grounded theory, termed Cultivating Knowing and Relationships represents the social-psychological process between CNAs and residents as death approaches. Focus on relevant aspects of the CNA-resident relationship reveals both inter- and intrapersonal processes as well as shifts in knowing, meaning, and understanding. Understanding the intimate nature of this relationship is undergirded by revealing layers of knowing and the evolution of what is ultimately a deeply emotional relationship. CNAs come to know the residents' likes and dislikes, their behavior, and ultimately who they are as individuals. This cultivation is further nurtured as the residents decline to death, at which time knowing becomes most poignant. CNAs give voice to their own experiences as well as giving voice to the residents as they know and understand them.

CHAPTER FIVE: DISCUSSION

Introduction

This emergent mode grounded theory study sought to verify and refine the

preliminary concept of quality of death through prospective inquiry into palliative care in

the nursing home.   Prior to this study, quality of death was retrospectively constructed

from literature on palliative care in the nursing home setting. The quality of death

theoretical matrix served as a framework as I engaged individuals involved in palliative

care in the nursing home using grounded theory methods. Informed by Symbolic

Interactions and Social World and Arena Theory, I looked for the influence of arenas and

social worlds and social interaction between individuals. Donabedian's attributes of

quality: acceptability, legitimacy, and equity, guided my investigation into the presence

and meaning of quality in the death experience. As a result, the Grounded Theory

Cultivating Knowing and Relationships emerged.

Cultivating Knowing and Relationships relies on several salient dimensions of

quality of death, yet spans a much larger and more dynamic social-psychological process.

Cultivating Knowing and Relationships focuses on the CNA-resident relationship and the

unique way CNAs come to know their residents, ultimately facilitating quality of death.

Quality of death, therefore, is a refined concept embedded in the larger Grounded Theory,

Cultivating Knowing and Relationships (see Figure 4). This chapter begins by describing

quality of death as a refined concept as it relates to Cultivating Knowing and

Relationships. Next, the significance of Cultivating Knowing and Relationships in light

of current understanding is explored. A discussion of the ethical issues with regard to the

ethical impact and boundaries of the study follows. Finally, future directions for research

and practice posed by this emergent mode grounded theory are detailed.

Quality of Death

Verification and Refinement

As described in Chapter One, quality of death was constructed via a dimensional

analysis using the five matrix components. These are perspective, context, conditions,

processes, and consequences. Dimensions that emerged through the dimensional analysis

process were subsequently assigned according to the five categories and finally arranged

into a theoretical matrix. Broadly, the findings from this prospective study verify many

of the dimensions present in the preliminary concept of quality of death (Figure 1).

Through Cultivating Knowing and Relationships, these dimensions are refined based on

their theoretical emergence in present analysis.

Perspective

Communication was the overarching perspective of quality of death.   It

represented concrete verbal communication about all aspects of palliative care amongst

all individuals involved. In this study, communication was critical to the cultivation of

knowing and the nurturing of relationships though it did not appear as a stand alone axial

or theoretical code. In addition to verbal communication, however, unspoken

communication was critical to the CNA-resident relationship. Residents rarely

communicated with words. Rather, they used gestures and behavior to communicate

their needs. CNAs developed an understanding of their residents' language through the

cultivation of knowing, which resulted in deep and meaningful relationships. CNAs and

other also communicated through gestures such as holding hands and being with the

resident as death unfolded. Communication in Cultivating Knowing and Relationships, therefore, is a subtle yet meaningful dimension.

Contextual Elements

The quality of death matrix highlighted *Nursing Home Factors* of regulations and paperwork, lack of palliative care-related *Knowledge and Education*, and *Role and Staffing Issues* as significant contextual limitations to the potential for successful palliative care delivery. In particular, current research highlights the high rate of burnout among CNAs as evidenced by staff shortages and frequent staff turnover(Castle & Engberg, 2005). The physically demanding nature of CNA duties, high CNA-resident ratios, diminishing resources, and little appreciation in return for their efforts are the main reasons for continued problems. While these problems are real, Cultivating Knowing and Relationships calls attention to the emotional bond between the CNA and resident, a rarely explored phenomenon.

The lens of SWAT revealed the NH as an arena in which various social worlds exist. This arena dictates a professional context where CNAs are assigned to provide specific care to residents. Contrary to current perceptions, SWAT facilitated the discovery that emotional rather than regulatory boundaries circumscribe the NH arena. Within this arena, CNAs create social worlds for the residents through their carefully cultivated relationships and imbued personas. In addition, reciprocity fosters the evolution of CNAs' own personal social worlds. These data indicate CNAs also develop social worlds amongst themselves. They share an implicit understanding of what it means to care for institutionalized and socially disenfranchised individuals as they die.

In this study, CNAs stressed the difficulty of balancing professional

responsibilities with watching the residents they have come to love decline and

eventually die. Saying goodbye and moving on from the loss of the relationship are

aspects of the CNA role that make it mentally and emotionally taxing. Without carefully

maintained social worlds, CNAs may lack the social and emotional support necessary to

do this work. This phenomenon, however, is largely unexplored in current literature.

Conditions

  Humanism was one of the conditional elements in the preliminary concept

description of quality of death. In constructing the theoretical matrix of quality of death,

humanism required significant theoretical interpretation, given it was not explicitly

present. In addition, the lack of humanism was theoretically tied to negative outcomes

portrayed in the literature (Trotta, 2007). In this analysis, however, the importance of the

theoretical connection between humanism and quality of death was pivotal. Humanism

was highly verified via the cultivation of knowing and acting on knowing. It was vastly

more important than the peripheral position it had in the literature from which the

preliminary concept was constructed.   Expressions of compassion and concern for the

residents were prominently featured as existential knowing was cultivated and CNAs

stewarded residents to their deaths and beyond.

  Advance Care Planning (ACP) and *Trajectory and Prognosis*, the other

conditional elements of the preliminary concept of quality of death, were present but not

nearly as prominent. While many residents had formal written advance directives in

place, from the CNAs perspective, ACP consisted of acknowledging death and acting in

accordance with what they believed to be the resident's wishes. The literature

encourages a formal determination of a prognosis, which is typically the designation of

dying within a particular time period, prior to care that is palliative in nature (Castle &
Engberg, 2005; van der Steen, Mitchell, Frijters, Kruse, & Ribbe, 2007; Wallace &
Prevost, 2007). What emerged in this analysis, however, was CNAs' implicit
understanding that death would occur, and that palliation was the ultimate goal. Given
CNAs provide the majority of care for those who ultimately die in NHs, understanding
and incorporating their perspective would likely enhance quality of care.

The practice of relying on the declaration of dying in advance of death was
largely absent in this study. This can likely be explained by a combination of the
profound presence of humanism and CNAs' approach to care. Humanism was
foundational, rather than reliance on advance directives and clinical prognostic
algorithms. Perhaps most profound was the CNAs' ability to anticipate death simply by
knowing the resident and detecting subtle changes. CNAs expressed humanism through
cultivation of knowing, which is antithetical to contemporary understanding of ACP and
determination of prognosis. Furthermore, CNAs relied on an existential awareness of
dying based on their knowledge of and relationship with their residents. They were often
able to accurately anticipate residents' deaths without diagnostics and other clinical data.
Given CNAs provide the majority of care for those who ultimately die in NHs,
understanding and incorporating their perspective would likely enhance quality of care.

Processes

In the preliminary concept of quality of death, the process of palliative care took
place through *Pain and Symptom Management* addressing *Psychosocial and Emotional
Issues,* and *Care*. Many of the themes present in the preliminary concept of quality of
death were verified in this study, yet some had more prominence than others. For

example, attention to pain recognition and alleviation was present in this analysis, but was unmatched by attention to hygiene care, comfort, and emotional attachment.

The preliminary concept of quality of death described *Care* as "all that is enacted under the umbrella of palliative care in the nursing home (p, 1122)." Clear articulation of this process in the literature was complicated, however, by circumscribed formalistic notions of what palliative care delivery should be. In this study, such formalistic notions of palliative care were not present. Care can not be dismembered into component parts, only to be recast as a sum and not a whole. Doing so fosters a fragmented and reductionistic view that often fails to meet the needs of those it is intended to help. Here, CNAs demonstrated a philosophical approach consonant with palliative care, embracing the holism required for the core social process of cultivation of knowing and relationships to unfold.

Consequences

Maintenance of a resident's *Personhood and Identity* was a requirement and immediate precursor for quality of death. Maintenance of *Personhood and Identity* included themes of dignity, respect, and being valued as a human being through death. This lead directly to *Quality of Death*, where death was acknowledged and prepared for according to the resident's wishes; and the experience of dying was embraced as important and meaningful for all involved. *Personhood and Identity* and *Quality of Death* emerged as pivotal themes in "Cultivating knowing and relationships." Current research demonstrates that maintenance of personhood and identity rarely occurs, making quality of death impossible (Kayser-Jones, 2002).

In the current study, maintenance of personhood and identity was very apparent element in the CNAs care for their residents. It stemmed directly from altruistic expressions of CNAs who provided intimate care for the residents through death. Details such as dressing the resident in her own clothes and shaving the resident so he looks like himself portray meticulous attention maintenance of personhood and identity through death. The findings of this GT strongly support the critical nature of preserving personhood and identity in ensuring quality of death for all involved.

In summary, quality of death as a retrospectively constructed preliminary concept served as a framework for the current study. Through verification and refinement, it was initially conceived of as having the potential ability to prospectively explain the social process of palliative care in the nursing home. Rather, a handful of dimensions that originally comprised quality of death are dissected from their explanatory matrix and are interwoven within the current GT.   Ultimately, while subtle aspects of other dimensions are present, *Humanism*, *Care*, and *Personhood and Identity* emerged as critically important to the larger social-psychological process, Cultivating Knowing and Relationships.

Significance of Cultivating Knowing and Relationships

Power of the CNA-Resident Relationship

In this study, I was especially privileged to discover the social world that exists between CNAs and their residents. This relationship is built around knowing as CNAs develop implicit understanding of their residents. Available research provides limited insight into the daily lives of nursing home residents that are approaching death and those who care for them. Appreciating the breadth and depth of this relationship, however, is

critical to improving understanding of the true process of care delivery in nursing homes.

The personal nature of the CNA-resident relationship clearly influenced the care dying residents in this study received. Kayser-Jones (2002, 2003) has portrayed the CNA-resident relationship as virtually nonexistent, and her observations of the care of dying residents revealed neglect and disregard for dignity. Through an ethnographic approach, she provides a vivid account of the lowest common denominator with regard to care of those who die in nursing homes. The present study, however, offers stark contrast to such findings. Cultivating Knowing and Relationships uncovers an intimate bond where CNAs come to love their residents and care for them as if they are family members. These dissonant findings beg for further investigations, across facilities and regions of the country.

Palliative Care

Palliative care is often described as a series of interventions aimed at ameliorating a series of problems, such as pain, shortness of breath, anxiety, or constipation, which may occur as individuals are dying. The palliative care model carries largely a biomedical perspective that directs thought and judgment toward specific actions and reactions. As noted above, however, the "care" that comprises palliative care cannot be dismembered and then reconstructed without losing the essence of what fundamentally maintains its cohesiveness: compassion and humanity. This study presents an arena where CNAs do not compartmentalize palliative care in such a fashion. It demonstrates that a biomedical frame is likely not fundamentally effective in meeting the human needs of dying residents. While allopathic care is clearly essential for control of pain and other

symptoms, the relational space that enables expression of respect and dignity seem to stand specifically apart from allopathic perspectives.

While addressing the physical needs of residents approaching death is important, this Grounded Theory highlights the compassionate care of CNAs who are taking direction from nurses and physicians, but also have a self-identified responsibility to care for the person and meet the personal, emotional, and humanistic needs of the individual. Knowing the resident as a person and valuing that person, especially at the time of death, emerged as critical to quality of death. Current conceptualizations of palliative care only tangentially addresses such issues, and provide scant information from which to address such issues (Travis, et al., 2002). This study supports a departure from traditional biomedical perspective of what constitutes palliative care to one that embraces the humanistic needs of the individual and preserves personhood through death. Further study that explicates and exposes frames of understanding must undergird advancements in end of life care for dying residents.

Applying the Label of Dying and Prognosticating Death

A shift in care from a "curative" to a "palliative" model typically occurs with the designation of dying. While contemporary research supports incorporating palliative measures in tandem with curative measures for a smooth and overlapping transition, palliative care in its fullest sense is often not embraced until an individual is designated as "dying" (Lynn & Adamson, 2003). For nursing home residents, research shows this label is often applied very close to death or not at all (Trotta, 2007). This is largely due to prognostic difficulty; given nursing home residents have multiple chronic illnesses of equal severity. Incorporation of palliative care into the nursing home setting is also

infrequent, possibly contributing to reluctance in specifying "dying." Together, these issues limit the resident's opportunity to receive any type of palliative care.

This Grounded Theory describes a population of residents designated as receiving palliative care. As noted in Chapter Three, the organizational culture and philosophy of palliative care at Community Geriatric Center embraces a palliative care philosophy that does not rely on designating dying in advance of death. In fact, the term "dying" was rarely verbalized among study participants. This results in an arena where CNAs are given implicit permission to act on their humanistic instincts rather than rely on a biomedical determination of dying. Additionally, the findings demonstrate CNAs' lack of distinction regarding palliative care status in their approach to care. While this philosophy may be unique when compared to other nursing homes, it appears to be critical to ensuring quality in death. Inquiry into the nexus of organizational structures and delivery of care is warranted to better understand the effects of organizational philosophy and administration on individual resident experience.

The CNAs in this study demonstrated astonishing success in knowing when their residents are going to die. Through cultivating knowing and relationships with their residents, they are able to detect subtle changes which ultimately serve to predict death. They act on their assessments, amplifying aspects of care, adding intricately developed details, and communicating changes to the nurses with whom they work. Thus, they appear able to ensure quality of death, because they ultimately meet the humanistic needs of all residents in advance of death and through death. This study supports the possibility that knowing the resident, which results from a carefully cultivated relationship, can facilitate the determination of relative closeness to death. Such an addition to current

methods may have utility given current methods alone have consistently led to missed

opportunities to provide care that is palliative in nature (Steinhauser, et al., 2000;

Strumpf, et al., 2004; Wetle, et al., 2005)..

Ethics

Ethical Issues With Regard To Study Methods

Conducting research with vulnerable populations

Residents. At the outset of this study, would-be index residents were immediately

perceived of as a vulnerable population. Cognitively impaired individuals at the end of

their lives residing in an institution represent a triple threat with regard to vulnerability.

Initially, current discourse shaped my perception that research involving observations of

personal care with such a population was highly intrusive and carried significant risk for

emotional and personal burden. Researchers continue to debate the most appropriate way

to involve such a population in research given these perceived risks. In this study, I

employed a variety of safeguards to protect the residents from involuntary participation in

research and emotional or physical harm as a result of participation.

Studies that enroll cognitively impaired individuals often have complicated

protocols for assessing cognitive capacity and decisional capacity in light of the

perceived risks of the study. Due to their complexity, such protocols have the potential to

stymie enrollment both at the institutional level and the individual level. Instead of using

discrete measurements of cognitive function periodically over time, for example, the

Mini-Mental Status Exam, I found a more general perspective more helpful and less

burdensome to participants.

When death is expected, cognitive function is also likely to decline. I conducted this study from the perspective that all index residents had at least moderate cognitive impairment, which was verified by the medical director, and all residents' capacity would decline over the course of the study. By safely assuming that each resident lacked decisional capacity at the outset and ensuring safeguards like proxy consent, changes in cognitive function over the course of the study were irrelevant.

Use of proxy consent in light of a broadened perspective of cognitive impairment is an advent in the conduct of a study such as this. My experience in using proxy consent with resident assent or lack of dissent in this study was successful and proved to be an acceptable strategy for these study participants and those responsible for their well-being. Only one of the 26 proxies I contacted declined participation for her loved one. Interestingly, proxies appreciated the opportunity to share their loved ones' stories and have their loved ones' experiences potentially impact the care of others. Successful conduct of this study supports a growing body of evidence that involving cognitively impaired nursing home residents in research via proxy consent allows for access to a population that would be otherwise voiceless.

Certified nursing assistants (CNAs). CNAs are not recognized as a vulnerable population in research. Over the course of this study, however, I found them to be potentially more vulnerable than the residents. As noted in Chapter Three, CNAs can be a marginalized group for a variety of reasons. While CNAs certainly faced moral and emotional distress, they seemed to have a strong support system in place with their co-workers. Furthermore, CNAs' theoretical achievement of gratification in their work likely supported their ability to manage the distress.

Fear of repercussions is gaining attention as a potentially serious ethical problem for a variety of reasons (Danis, et al., 2008). While fear of repercussions did not surface as a serious issue in the present study, its potential for negative consequences was evident. Fear of repercussions among CNAs, namely the loss of their job or other punitive damages as a result of participating in a research study, requires further investigation. This fear is significant given many research reports paint CNAs and the products of their work in a negative light. Minimal guidance exists with regard to protecting such a population. While safeguards were in place for CNAs in the present study, they could have potentially been inadequate. Guidelines for safeguarding CNAs need to be developed and codified. These steps are especially necessary given the need to engage CNAs in future research on nursing home care.

Ethical Issues With Regard To Study Findings

Cultivating Knowing and Relationships is a practical theory with significant ethical undertones. In this study, CNAs maintained respect for human life through death by providing ethically sound, compassionate care. Faced with the option to provide nothing more than basic hygiene care as residents neared death, they sat with residents, held their hands, and prayed for them. They cultivated deep emotional and personal relationships. This could be viewed as a serious breach of personal boundaries and potentially unethical from a biomedical perspective. To these CNAs, however, doing anything less would be dehumanizing.

The concept of dignity is gaining prominence as a desirable and important aspect of care for those dying in nursing homes (Franklin, Ternestedt, & Nordenfelt, 2006; Pleschberger, 2007). While lack of attention to dignity at end of life may be considered

unethical, preserving dignity can be difficult understand in a purely biomedical or allopathic frame. Currently, little guidance exists regarding means and methods to preserve dignity. This is perhaps because extant research on death in nursing homes assumes a biomedical perspective. In contrast, this grounded theory provides insight into the way CNAs preserve dignity for their residents. Delineating CNAs' and other staff members' actions and exposing links to preservation of dignity offers new directions for research in end of life care in nursing homes.

Study Boundaries

Community Geriatric Center is a large, urban, not-for-profit NH. The population of both staff and residents is culturally and ethnically diverse. Furthermore, CGC is likely unique in that it embodied a palliative care philosophy. While not directly examined, this philosophy likely had some influence on the CNAs' approach to care. Therefore, further investigation is necessary in nursing homes with a variety of philosophies, and of various sizes and locales. Additionally, this situation specific grounded theory offers conceptual relevance for similar institutions and individuals. Application of it requires careful consideration of context, organization, and implications.

Directions for Future Research

Cultivating Knowing and Relationships offers a novel perspective on the care of those who die in nursing homes. It reveals a practical theory of a process that is invisible to those who claim to understand palliative care and frail older people. This theory sheds light on human care, which until this point has been overshadowed by an allopathic approach to care at the end of life. It is about being with people through their last days and moments; ensuring preservation of personhood and dignity for those who can not

preserve it for themselves. While sound medical and nursing care are critical, this study

provides an opportunity to understand what constitutes quality in death. Research that

continues to focus on quantifying nursing interventions and teaching CNAs about

palliative care according to an allopathic perspective will undoubtedly continue to fall

short of expectations. Rather, consideration of alternatives to biomedically dominant

investigation into improving palliative and end of life care for nursing home residents and

other individuals who have reached the end of their natural life spans may provide

counterpoint to necessarily reductionist analyses of care components and redirect care

strategies.

Current markers of quality care in NHs, such as prevention of weight loss,

prevention of pressures ulcers, and treatment of pain are important to ensure

accountability against neglect. These markers, however, fail to address what seems to

matter most to those experiencing death in the nursing home. This theory illuminates

CNAs' desire and ability to deliver care acceptable, legitimate, and equitable care to

dying residents.   They did so not only through the tasks they completed, but also through

the manner in which they interacted with the residents while completing such tasks.

CNAs focus most of their time on feeding and hygiene care. For independent self-

sufficient human beings, these are two of the most personal and fundamental aspects of

life. For those who lack capacity, being fed may prevent weight loss and thus meet a

standard of quality care. Similarly, being bathed regularly will likely prevent a urinary

tract infection, another standard of quality of care. In this study, however, CNAs did

much more than meet current conceptualizations of quality care.

The CNA-resident relationship that emerged in this study offers a vastly more whole, and less compartmentalized notion of quality. Quality did not appear to be judged by traditional measures in this study. CNAs purposefully situated these residents in reciprocal relationships which transcend traditional notions of quality. In caring for dying residents with whom they had a personal relationship, CNAs judged the quality of the care they provided by measuring it against they way they would want to be treated as they died. Further refining the conceptualization of quality of death, therefore, may have continued utility in identifying and creating meaningful measures of quality.

Finally, this work has the potential to serve as a foundation for future nursing inquiry. First, while I did not intend to focus solely on the CNA-resident relationship, its importance was illuminated through the analysis. A focused examination of the CNA-resident relationship can confirm and build upon the findings of this study, ultimately revealing avenues to improve the quality of care delivered to those who die in NHs. Second, this study only tangentially examined the influence of organizational culture and the professional context. A longitudinal study focused on the influence of organizational culture on the CNA-resident relationship will provide insight into this important variable in the delivery of care. Third, viewing this study in light of available knowledge demonstrates the paucity of understanding about the CNA. Development of a situation-specific theory is necessary to begin to fully understand how CNAs care for dying residents and what motivates them to do what they do. By engaging CNAs who care for frail vulnerable residents, we can begin to lay a foundation of theoretically sound and clinically relevant research. Additionally, further theoretical refinement will strengthen a

trajectory of research aimed at improving quality of care and evaluating it according to

meaningful outcomes.

Figure 1. Quality of Death Dimensional Analysis Matrix
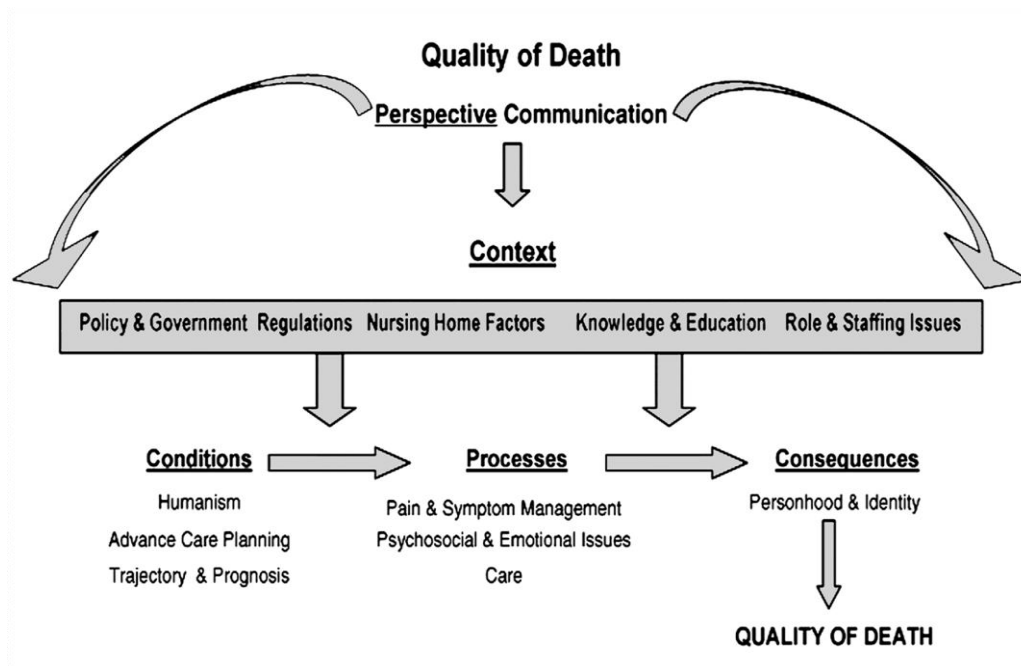
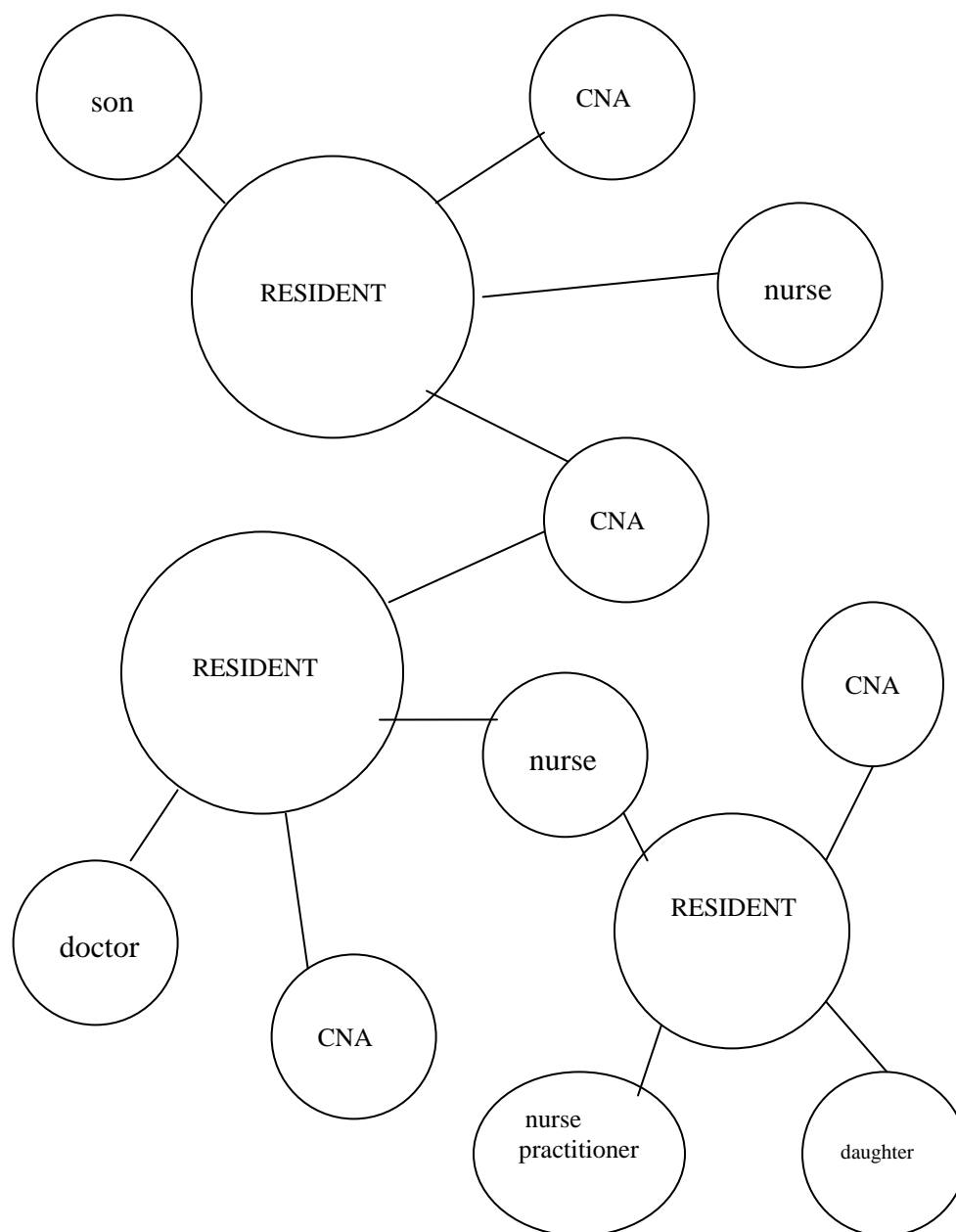Figure 2. Example Schematic of Index Residents and Secondary Participants

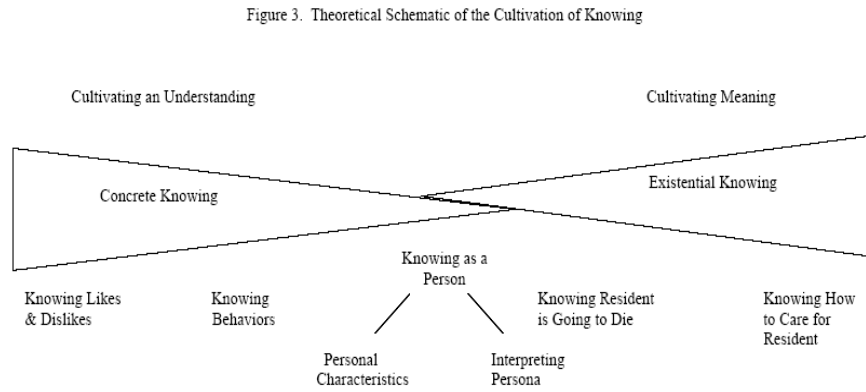Figure 3. Theoretical Schematic of the Cultivation of Knowing

Figure 3. Theoretical Schematic of the Cultivation of Knowing

Cultivating an Understanding   Cultivating Meaning

Concrete Knowing   Existential Knowing

Knowing as a
Person

Knowing Likes   Knowing   Knowing Resident   Knowing How
& Dislikes   Behaviors   is Going to Die   to Care for
                                                                              Resident

Personal   Interpreting
Characteristics   Persona

Figure 4. Theoretical Schematic of Cultivating Knowing and Relationships

Cultivating Knowing and Relationships Theory Schematic
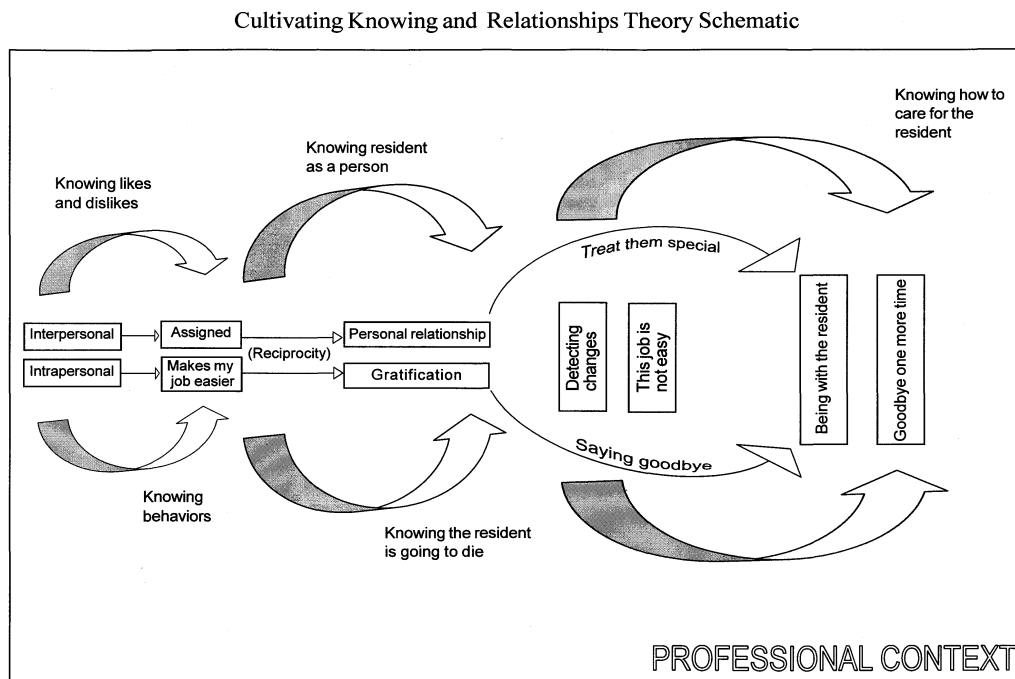
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All names have been changed to protect the identities of the participants.