

Doing the Right Thing: Relational Ethics in Institutional Caregiving for Veterans

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ABSTRACT

This research explored psychological, social, and relational aspects of caregiving. It examined documented resolution of ethical dilemmas precipitated by veterans' medical crises and involved formal caregivers, informal caregivers, and veteran patients. The unit of analysis was caregiving relationships.

The main research question asked, how does case documentation and documented processes of resolving ethical dilemmas in institutional healthcare for veterans reflect relational ethics?

Relational ethics was defined as fairness of interpersonal give and take and included efforts to elicit, understand, and honor veteran's values and care preferences.

The caregiving context was a Veterans Affairs Medical Center (VAMC). The research population was 25 male veterans whose cases required intervention by the VAMC ethics committee. The research was conducted in three phases using grounded theory methodology.

The research purpose, guided by symbolic interaction theory, was to develop substantive theory in relational ethics. Study analyses used *Atlas.ti* qualitative software.

Main study one, Veteran-Formal Caregiver Relations, focused on relational processes internal to the VAMC. It explored how members of professional healthcare disciplines documented ethical caregiving concerns amongst themselves and in interactions with veteran patients. Agency emerged as the core category. Agency meant that veteran patients could make choices and act on

those choices in ways that impacted their care. When veterans' agency was compromised, formal caregivers' roles became more salient. The substantive theory was the **dynamic process of clarifying agency**.

Main study two, Formal-Informal Caregiver Relations, focused on interactions between VAMC staff and veterans' significant others. It explored medical center staff communications with informal caregivers regarding veterans' health problems. Documented interactions confirmed the impact of relational ethics. Agendas and advocacy emerged as key categories that determined and respected veterans' relational autonomy. Relational autonomy validated other ethical concerns and resource demands, considered social context, and included obligations as well as entitlements. The substantive theory was the **agenda to advocate for relational autonomy**.

Substantive theories from the two main studies were integrated. Categorical dimensions were combined into substantive theory; that doing the right thing in institutional caregiving for veterans was the **dynamic process of clarifying agency with the agenda to advocate for relational autonomy**.

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Dedicated to the many and varied relationships
past, present, and future
which enrich and empower my life

To Family, Friends, Shipmates, Neighbors, Colleagues, Mentors, and Veterans...

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CHAPTER 1 - INTRODUCTION

Reflecting on how our personal experiences relate to academic inquiry improves transparency and critical analysis of the knowledge we produce (Allen, 2000). Careful consideration of researcher investment and interest in the study phenomenon is necessary throughout the research process, from inception through interpretation, and contributes to the integrity of our efforts (Daly, 2007). This research begins with a personal story from 42 years ago.

Personal Reflection

By October of 1966 I had been stationed in the Far East for over 30 months. I was a U.S. Air Force communication and navigation flight line technician in the 13th Tactical Fighter Squadron (TFS), and part of the U.S. Pacific Air Forces. We were supporting a flight of F-105, *Thunderchief*, fighter-bombers flying daily, hazardous, bombing missions into North Vietnam. The Royal Thai Air Force base supporting our operations was in Korat, at 14 degrees 58 minutes north latitude, about 900 nautical miles north of the equator. We worked long, tropical-hot days on a concrete apron parallel to the flight line.

One day I began passing out every few hours and went to the infirmary to see what was wrong. I was immediately diagnosed with infectious hepatitis, along with malaria-type symptoms, and assigned to a cot in sick bay. A few days later I was flown to Tachikawa Air Force base in Japan. My discharge from the hospital (Walter Reed Army Medical Center in Washington, D.C.) and Air Force active duty, came about three months later, on January 25th of 1967. By then I had spent over three months as an inpatient at two separate military medical centers.

In 1966 Tachikawa Airbase served as a major Casualty Staging Facility for the Vietnam War. This meant that every few days, sometimes daily, flights arrived directly from the frontlines in Vietnam. Many of the men were terribly wounded with missing limbs, large visible lacerations left open to heal, obvious signs of battle fatigue, and trauma. Men sometimes screamed at night, lived out recent firefights in the early morning, or played boisterous card games with invisible fellow soldiers in the evening.

Many memories of that time are disjointed and vague, others vivid and clear. I remember lying in a bunk bed in one wing of a round-roofed, Quonset-hut-type building. I spent many hours there, for five or six weeks, as a steady stream of wounded comrades came and went. They

usually stayed no more than a day to two and were quickly shipped to medical facilities close to their homes, Stateside. Those few of us with less obvious and traumatic wounds stayed put. Our mandatory uniform, all day everyday, was light blue pajama tops and bottoms, a dark blue cloth robe, and dark blue house slippers. There was no mistaking the patients; we wandered around the base, blue. There are vivid memories of watching movies in a large darkened room conscious of the projector flashing light and shadows across wounded faces and bodies. I remember mornings going into the large latrine, bathroom, with a line of sinks and a long mirror that reflected an every changing sea of faces, all young and physically mutilated men. I never heard a single complaint, not one.

This research reawakened memories from over four decades ago that helped me understand my intense motivation for the project and why I recognized factors such as agency and autonomy as salient in the theory that emerged. I now understand the trauma of that time as patient, why many nights, in spite of a damaged liver, I stuffed my bunk with clothing and took the train to Tokyo to drink alcohol, and why I can't remember many details of that fall and winter, not even if I made it home in time for Christmas with my family.

Through this research process, and the memories it triggered, I recognized the profound impact of the lack of any meaningful relationships during my time as military patient. We had all been abruptly torn from one of the most intense web of relationships that we would probably ever experience. Our friends were left behind; for me, Lupe, Rich, and Clyde. Although I am by nature very social, I cannot recall connecting with anyone for many months after leaving the military. Hopefully these memories, which resurfaced during the final weeks of dissertation writing, will explain why a commitment to ethical care for veterans and the importance of relationship are at the heart of this research.

Relational Ethics Defined

Relational ethics was central to this exploration of efforts to provide ethical caregiving for veterans. Relational ethics is generally defined as perceived fairness of interpersonal give and take (Boszormenyi-Nagy & Krasner, 1986; Van Heusden & Van Den Eerenbeemt, 1987), with fairness described as balancing what we are entitled to receive and obligated to give (Hargrave & Pfitzer, 2003; O'Neill, 2002). In healthcare, relational ethics is also conceived as a *third entity* between interacting persons, a *relational* or *ethical* space, that required attention and nurturance (Bergum & Dossetor, 2005). This relational-ethical space was empowered and nurtured through

mutually respectful engagement, freedom of choice, acknowledgement of uncertainty and possibility, and a supportive environment.

In this study, the understanding of relational ethics evolved. The definition retained fairness and ethical-relational space elements and came to include concerted efforts to elicit, understand, and honor veteran patient's values and wishes. With development of substantive theory, the measure of relational ethics in each enactment of caregiving was understood as the congruence between care provision and veterans' appropriate, autonomous, care preferences.

Relational autonomy, to be discussed in more detail in chapter five, was defined in caregiving context (MacKenzie & Stoljar, 2000) and considered veterans' autonomy in interpersonal terms that validated other ethical concerns and resource demands. Relational autonomy was also conceived as principled autonomy (O'Neill, 2002) that linked obligations to rights, as viewed in turn by recipients (veteran patients) and actors (caregivers). Principled autonomy echoed relational ethics' sense of fairness in balancing entitlements and obligations. The desired outcome in both conceptualizations was to build trust and trustworthiness (Boszormenyi-Nagy & Krasner, 1986; Hargrave & Pfitzer, 2003; O'Neill, 2002). The research explored relational ethics in caregiving for veterans.

Research Overview

The 25 veteran patients involved in this study were immersed in caregiving relationships at a Veterans Affairs Medical Center (VAMC). Each veteran was faced with serious and complicated caregiving dilemmas. These dilemmas included mental and physical health crises, end of life and quality of life issues, choices between aggressive attempts to cure and providing only comfort care, and differing opinions of veteran's communication capacity, care needs, and preferences.

The 25 documented stories of resolving these dilemmas were inherently relational; veterans communicated with nurses and family members, doctors with doctors and social workers, chaplains with veterans and psychologists, within a web of relationships. The focus and ethical challenge of their interactions was to determine the right course of action and to continually reevaluate progress, changing course if necessary, as circumstances changed. Therefore, the chosen unit of analysis was caregiving relationships, with particular focus on relational meaning and decision making processes.

The research was qualitative and exploratory, guided by symbolic interaction (Blumer, 1969; Burke, 2003; Mead, 1934) and social structural symbolic interaction (Stryker, 1980; Stryker & Burke, 2000) theories. Grounded theory methodology (GTM), as detailed in chapter three, was used to develop substantive relational ethics theory in caregiving for veterans. As stated, the specific caregiving environment of this study was a Veterans Affairs Medical Center. The care recipients were 25 military veterans from the baby boom and other generational cohorts in need of inpatient institutional i.e., hospitalized, care. Within that social structural caregiving environment, the research explored the psychological, social, and relational aspects of documented efforts of the ethics committee and others to assess and resolve aforementioned ethical dilemmas. The intent was to better understand decision making processes involving formal and informal caregivers, and veterans receiving care, facing difficult healthcare choices.

The relational process of deciding on the right thing to do in these 25 complex caregiving cases required the involvement of the VAMC ad hoc ethics committee. The committee, sometimes referred to as the ethics team, convened when an ethics consult was requested. The multidisciplinary, 25-member committee included professionals such as nurses, doctors, social workers, and chaplains. Members participated in team meetings based on schedule and availability. There was a concerted effort to insure that at least two professional caregiving disciplines were in attendance. The purpose of the committee was to help resolve emergent ethical dilemmas in care provision by making specific case-by-case recommendations.

The research population of 25 male veterans represented all cases between October 2003 and January 2008 that required intervention by the VAMC ethics committee. The documentation data source for all 25 veteran case files was the VAMC *Computerized Patient Record System* (CPRS). The CPRS documented and archived thousands of daily progress notes, assessments, case histories, reports, consultations, and discharge summaries for the study population cases.

First, feasibility and pilot studies were completed. Then a main study, consisting of two archival studies, was conducted using grounded theory methodology. Pilot and main study analyses used *Atlas.ti* qualitative software to record codes, categories, memos, and quotations while creating and managing conceptual linkages of emerging substantive theory.

Main study one, Veteran-Formal Caregiver Relations, focused on case documentation describing relational processes internal to the VAMC. It explored how members of professional disciplines (e.g., doctors, nurses, chaplains, and social workers) documented relational issues and

ethical concerns amongst themselves and in interactions with veteran patients. Documentation of caregiving relations within the VAMC reflected the impact of participation processes, social structure, role salience, and veteran's perceptions on ethics committee recommendations and dilemma resolutions. Agency emerged as the core conceptual category and veteran's agent as the most salient role. Agency meant that veteran patients could make choices and act on those choices in ways that impacted their care (Martin, Sugarman, & Thompson, 2003). When veterans' agency was physically or mentally compromised, formal caregivers' roles as veteran's agents became more salient.

Main study two, Formal-Informal Caregiver Relations, focused on case documentation describing interactions between VAMC staff and veterans' significant others. It explored ethics committee member and medical center staff communications with veterans' informal caregivers, family, and friends regarding veterans' health problems. Investigation of formal-informal caregiver relations discovered psychosocial and ethical issues not apparent in study one. These documented interactions confirmed the impact of relational ethics processes, as understood from the varied perspectives of ethics committee members, medical center staff, and veteran's significant others, on attempts to reach agreement on recommendations and decisions to resolve ethical dilemmas.

The emergent core concept from study two was agenda, to determine, respect, and advocate for veteran care recipients' autonomy. The ethical agenda was to determine and promote things to be done or considered in providing care desired by autonomous veterans. This research process moved beyond understanding autonomy as individualistic self-governance free of personal limitations and outside interference. Relational perspectives that considered veterans' autonomy in social structural and interpersonal context discovered advocacy for relational autonomy that validated other ethical concerns and resource demands.

The two studies were linked by their focus on psychosocial and relational elements of case documentation that reflected perceptions, descriptions, and evaluations impacting the ethics of caregiving, decision making processes and outcomes. They differed in role-relationship focus. Study one explored how formal caregivers, as members of professional disciplines, operating in roles such as doctor, nurse, and social worker, identified and processed ethical concerns between themselves and with veteran patients. It focused on documented communication internal to the VAMC. In contrast, study two explored ethical aspects of communication between formal

caregivers at the VAMC and veterans' informal caregivers and significant others in roles such as spouse, family member, friend, or concerned other. Investigation of interactions between staff of the VA Medical Center and members of the veteran's informal care system discovered relationship challenges related to differing roles, language, culture, and values not apparent in study one.

The outcome of the research was the development of substantive theory, grounded in the data, which confirmed a contextual, relational process of resolving healthcare dilemmas. The theory stated that doing the right thing, and thereby actualizing relational ethics in institutional caregiving for veterans, was the dynamic process of clarifying agency with an agenda to advocate for relational autonomy; a process that sought to determine who had agency and to what degree, whether agency agendas honored veterans' autonomous values and needs without ignoring larger ethical, relational, and resource issues.

Research Metaphor

It has been suggested that, "metaphor is a very useful conceptual tool for beginning to theorize about contemporary families" (Dilworth-Anderson, Burton, & Klein, 2005, p.46). Although family involvement is only part of this study, the use of metaphor helps to clarify presentation of a complex phenomenon and resultant research.

Imagine the researcher's initial personal reflection as one scene in a play about caregiving for veterans. The scene has a main character and cast of supporting actors; the setting is a military medical center. The research presented here examines 25 caregiving plays. The main characters are all veterans. The curtain has come down on 18 of those plays; the veterans are deceased. The cast of supporting actors includes formal and informal caregivers. Each veteran main character is in crisis. A serious mental or physical health problem has brought them to a Veterans Affairs Medical Center (VAMC) for care. The dramatic tension is in efforts to determine and do the right thing for each veteran.

Examination of these 25 plays about veterans was limited since the data included only written entries made by actors in the formal caregivers group. However, their documentation of scenes and dialogues surrounding the main character highlighted important aspects of relational ethics in best efforts to do the right thing for every veteran.

Purpose and Potential of the Research

This research began with the intention to better understand relational experiences and challenges of formal and informal caregivers and care recipients in resolving veterans' ethical caregiving dilemmas. The overall aim, to develop substantive theory with the potential to describe, explain, and promote improved relational ethics and outcomes in caregiving, was met. The resultant substantive relational ethics theory described the dynamic process of clarifying agency with an agenda to advocate for relational autonomy. It helped to clarify the ethical dilemma resolution process and suggested dimensional properties linking the concepts of agency, agenda, advocacy and autonomy with the potential to operationalize the process. The theory's potential to promote improved veteran's medical care outcomes will be discussed in chapter six.

Department of Veterans Affairs and Caregiving Challenges

The Department of Veterans Affairs (VA) mission statement is "To fulfill President Lincoln's promise – 'To care for him who shall have borne the battle, and for his widow, and his orphan' – by serving and honoring the men and women who are America's veterans." The VA vision is "To provide veterans the world-class benefits and services they have earned – and to do so by adhering to the highest standards of compassion, commitment, excellence, professionalism, integrity, accountability, and stewardship" (Department of Veterans Affairs, 2008).

Providing veterans with the care they have earned is a daunting proposition. According to the Federal Interagency Forum on Aging Related Statistics report *Older Americans Update 2006 – Key Indicators of Well-Being*, "in 2000 there were 9.8 million veterans over age 65 in the United States and Puerto Rico...two of three men over age 65 were veterans" (Federal Interagency Forum on Aging Related Statistics [Forum], 2006, p. 10). More recent data from the Veterans Affairs (VA), Veterans Health Administration (VHA), on *VA Benefits and Health Care Utilization*, updated on January 24, 2008, indicated that the total number of veterans was 25,532,000, with about 7%, or 1,745,000, being female; of those, 7.8 million were enrolled in veterans healthcare as of fiscal year 2007 (Veterans Health Administration, Statistics, 2007). Veterans' healthcare program enrollment began in 1999 with a total of 1.4 million enrollees; the 7.9 million enrollments in 2007 represented an almost five fold increase in only eight years.

Veteran's Military Service and Earned Support

In recent congressional testimony United States Senator Gordon H. Smith of Oregon, speaking before the Committee of Senate Special Aging, about health care for aging veterans stated:

There is no greater obligation than caring for those who have served this country with their military service. We would be remiss if we did not ensure that the health care of our heroes in arms is the finest medicine has to offer. While much of the focus in the media has been centered on the state of health care for our returning vets, it is the responsibility of this committee to not forget those who served in the wars of our past (FDCH Congressional Testimony, 2007).

By definition, all of the patients in the study population have served their country. Although only two served in combat, 20 of the 25 veterans served in time of war. Military personnel returning from Iraq and Afghanistan, besides being the focus of media attention, place significant strain on fiscal resources to meet the needs of all veterans (U.S. Government Accounting Office, Health Care Spending, 2007).

Those suffering serious, life-threatening health conditions, which describes all the veterans in this study, present social and emotional as well as physical care needs (Gordon & Benner, 1996). Eleven of the 25 veterans in this study served during the Vietnam era; one of the eleven was a Navy combat veteran. Veterans, especially from the Vietnam era, may present more demanding caregiving challenges to meet unresolved emotional needs such as late-onset stress symptomatology (King, King, Vickers, Davison, & Spiro, 2007). Vietnam was arguably our nation's most divisive war since the civil war. Of the estimated 3,143,645 men and 7,166 women who served in the Vietnam theater of operations, most were born between 1940 and 1949; they are now in or entering their 60s (Kulka, Fairbank, Jordan, Weiss, & Grady, 1990). These veterans along with those from earlier and later generations continue to increase the need for institutional care for veterans (Veterans Affairs [VA], Performance and Accountability Report, 2007).

It is important to note that military culture tends to discourage expressions of grief and intimacy and that Vietnam was primarily a guerilla war with no clear danger or safety zones, thereby presenting constant personal threats of violence, injury, or death (Sonnenberg, Blank, & Talbott, 1985). These factors can exacerbate the needs of veterans in general but the

controversial and unpopular Vietnam conflict denied those veterans the chance to discuss, and thereby decompress from, their traumatic experiences (Sonnenberg, Blank, & Talbott, 1985); as stated, 11 out of 25 or 44 percent of the veterans in this qualitative research, served during the Vietnam era. A recent study of trauma disclosure that included 147 veterans, 72 percent of whom were Vietnam veterans, found that many had disclosed their psychological distress only recently (Leibowitz, Jeffreys, Copeland, & Noel, 2008). In terms of doing the right thing, research indicates that caregiving ignoring psychosocial factors emphasized in this research may negatively impact biological outcomes as well (Newman & Newman, 2006).

Caregiving Crisis Contributing Factors

Several factors are contributing to a general crisis in caregiving, of which the veterans in this study are a part, including the *baby boom* population demographic, increased longevity, and formal-informal caregiver collaboration issues. These factors will increase caregiving demands and very likely the number and complexity of related ethical dilemmas. The process of deciding on the right thing to do i.e., making ethical decisions while respecting the relational needs of all concerned, will become more challenging (Gordon & Benner, 1996; Pellegrino, 1993). This ethical challenge, in the context of caregiver-care recipient relationships, requires attention to cognitive, behavioral, and affective aspects of care (Gordon & Benner, 1996).

The Caregiving Project for Older Americans: Caregiving in America (The International Longevity Center [ILC] & The Schmieding Center for Senior Health and Education [SCSHE], 2006) reports that we are in a caregiving crisis that will worsen with the aging of *baby boomers*. Awareness of the *baby boom* phenomenon has been with us for decades. *Boomers*, the large population cohort born after World War II, in the years 1946 to 1964, started turning 60 in 2006. They can be expected to live longer than preceding generations due to better understanding of behavior patterns that impact longevity (Erber, 2005) and medical advances.

The above report further documents fundamental problems of too few paid and unpaid caregivers and too many people in need of care. Those in need include about 6 million older Americans cared for at home, nearly 1.4 million living in nursing homes, and many others who go without needed support or fend for themselves. More to the point of this research, the report suggests the “need for better communication among medical practitioners, caregivers, and care recipients” (ILC & SCSHE, 2006, p. XI). The report stresses the tendency to treat formal and informal caregiving as two different worlds while in reality “it is rare for these two caregiving

systems not to interface in some way” (2006, p. 2). Our current and growing crisis calls for improved communication at individual and systemic levels and requires increased attention to the nature and quality of relevant caregiving relationships (Bergum & Dossetor, 2005).

Another factor contributing to a probable increase in ethical dilemmas in caregiving is that modernization in the 20th century has significantly increased the average longevity of all Americans. Life expectancy in the United States increased from 47.3 years in 1900 to 77.8 years in 2004 (National Center for Health Statistics, 2007). According to Omran (1971) this profound increase in longevity can be attributed to an *epidemiologic transition*, defined as a shift in patterns of mortality-related illness from acute infectious to chronic, degenerative diseases.

This transition resulted from improved sanitary practices, advancing medical technology, improved diets, and better control of parasitic and infectious diseases (Omran, 1971). In the late 1960s, life expectancy again trended upward due to state and federal health policies that favored older persons. Such policies, along with continued advances in medical science, led to significant declines in mortality due to major degenerative diseases, the resultant 1960s trend towards increased longevity was described as an additional stage of epidemiologic transition (Olshansky & Ault, 1986).

Beyond population and longevity pressures on access to formal and informal healthcare is the question of quality of caregiving environments and social interactions for both caregivers and recipients (Cleary, Freeman, Hunt, & Walter, 2006; Dauenhauer, 2006). Quality of care and caregiving decisions can be increased by improving the quality of formal-informal care relationships and interactions (Bergum & Dossetor, 2005). Such improvement promotes compensatory processes allowing informal care to substitute for formal care, and bridging processes where informal care facilitates formal care (Geerlings, Pot, Twisk, & Deeg, 2005). Whatever the caregiving environment, the degree of fairness of give and take in interpersonal relationships, one aspect of relational ethics, can significantly impact the quality of late life caregiving (Hargrave & Anderson, 1992).

Caregiving concerns for veterans, elders, and the critically ill are longstanding, but recent social and demographic changes suggest increasing challenges well into the 21st century. Given the described demographic impact of the aging baby boom generation, trends in epidemiologic transition, dramatic increases in longevity, formal-informal care collaboration issues, and compounding effects of military service, the number and complexity of relational ethics

dilemmas impacting caregiving choices (Benner, 2003; Day, 2007), and care-related quality of life (Veatch, 1998) are likely to increase.

Ethical Issues in Caregiving

For thousands of years our best attempts to answer both general and medical ethics questions were based on a synthesis of Greek Hippocratic precepts, Stoic concepts, and religious traditions, but since the mid-1960s there has been a perplexing metamorphosis in healthcare ethics (Pellegrino, 1993). This metamorphosis has further complicated moral dilemmas around issues such as medical specialization and depersonalization of healthcare, patient autonomy and physician-patient relationships, voluntary and involuntary euthanasia, as well as managed care and healthcare rationing. Pellegrino explains that metamorphosis in medical ethics as progressing through four overlapping historical periods of quiescence, principlism, antiprinciplism, and crisis.

Pellegrino (1993) makes five propositions of importance to this study: a) that we have entered the fourth period of *crisis*, when nihilism and skepticism have placed medical ethics in a dangerously subjective state b) that the four principles of principlism (autonomy, beneficence, nonmaleficence, and justice) should be retained to avoid relativism; c) that these principles should be supplemented with caregiving ethics based on virtue, casuistry, and caring; d) that ethical principles need to be grounded in the physician-patient relationship; and e) that medical ethics holds greater promise for grounding of principles, virtues, and rules than any other area of ethics because of the universal human experiences of illness and healing that are the immediate and long-term concerns of medical caregiving. This research expands on these five propositions by including emphasis on relationships other than between physicians and patients. It also embraces the invitation to use clinical bioethics as fertile ground for empirical research and, as a means to evaluate and develop substantive ethical theory.

Delivery of institutionalized healthcare, including VAMC care, profoundly changed in the latter half of the 20th century. Growing market and bureaucratic influences steadily overshadowed ethical agendas of researchers and healthcare practitioners, importance of community to human development, and needs for meaningful relationship (Bergum & Dossetor, 2005). In addition, modern cognitive bioethical approaches did little to guarantee ethical relational behavior in caregiving. Solomon R. Benatar from the Bioethics Centre at the University of Cape Town captured the problem as follows:

The scope and pattern of the bioethics endeavor has been considerably shaped by the notion that the world is made up of reflective, autonomous, self-determining individuals whose right to make choices for themselves is the most sacrosanct value in political life and in healthcare. The value of community and of relationships has been undervalued, and a dispassionate world of strangers has been constructed in which we are primarily responsible for only ourselves (Bergum & Dossetor, 2005, p. xii).

In contrast, the value of relationships was central to this research. Analysis discovered documented evidence of willingness of a relational community of both formal and informal caregivers to be ethically responsible for veteran patients.

In May of 2007 the Veterans Health Administration introduced *Integrated Ethics* (Veterans Health Administration [VHA], 2007) and began training on the concept at all 153 VA Medical Centers. The manual entitled, *Integrated ethics: Improving ethics quality in healthcare – Ethics consultation: Responding to ethics questions in health care*, states in the introduction that,

As the largest integrated health care system in the United States and a recognized leader in quality and organizational change, VA is now poised to take on a new challenge: to disseminate a systems-focused model to promote and improve ethical practices in health care – and a new way of thinking about ethics (VHA, 2007, p. 1).

and goes on to explain that ethics matter because,

Throughout our health care system, VA patients and staff face difficult and potentially life-altering decisions every day – whether it be in clinics, in cubicles, or in council meetings. In the day-to-day business of health care, uncertainty or conflicts about values – that is ethical concerns – inevitably arise (VHA, 2007, p. 1).

Further discussion states that when ethics concerns are not addressed there are negative repercussions for VA staff, patients, and society at large. The introduction quotes Donabedian (1979), considered the father of health care quality measurement, that quality in the medical caregiving context must include interpersonal quality defined as, “conformity to legitimate patient expectations and to social and professional norms” (p. 277).

As with this research, integrated ethics intends to empower “VA facilities and staff to ‘do the right thing’ because it’s the right thing to do” (p.5). The integrated ethics model targets three

VA systemic levels, decisions and actions, systems and processes, and environment and culture through ethical focus on consultation, prevention, and leadership.

This study was focused on consultation and interpersonal communication connected more directly with decisions and actions in closer proximity to the veteran patient. Research results were congruent with the intentions of the VA's ethics program and contributed to clarifying the process of ethical consultation and dilemma resolution with the potential to operationalize some elements of the intent of the integrated ethics agenda.

General and research-specific definitions of key terms used in this research are presented in Table 1. Relational ethics, care, and caregiving were key terms from the beginning of this qualitative exploration. Biopsychosocial and psychosocial terms became important early in the research process and helped guide emphasis on psychosocial data. Agency emerged as a key term and core category in study one, Veteran-Formal Caregiver Relations. Agenda, advocate, and relational autonomy were pivotal and core categories, respectively, in study two, Formal- Informal Caregiver Relations.

Chapter Two, following Table 1, describes the theoretical framework guiding the research.

Table 1

General and Research-Specific Definitions of Key Terms

| Key Terms | General & Research-Specific Definitions |
|---|---|
| <p>Advocate (The American Heritage College Dictionary, 2002)</p> | <p><u>G</u>: Speak, plead, or argue in favor of (p. 20) <u>RS</u>: Relationally, formal and informal caregivers speaking out and supporting perceived wishes and best interests of veteran patients; (oratory in the play)</p> |
| <p>Agency (Martin, Sugarman, & Thompson, 2003)</p> | <p><u>G</u>: Freedom of individual human beings to make choices and act on those choices in ways that make a difference in their lives (p. 44) <u>RS</u>: Veteran patients making choices and acting on those choices in ways that impacted their care; relationally, others could also act as veterans’ agent; (actors in the play)</p> |
| <p>Agenda (The American Heritage College Dictionary, 2002)</p> | <p><u>G</u>: A list or program of things to be done or considered (p. 25) <u>RS</u>: Relationally, ethical agenda to determine and promote things to be done or considered in providing care desired by autonomous veterans; (script for the play)</p> |
| <p>Relational Autonomy (Mackenzie & Stoljar, 2000; O’Neill, 2002)</p> | <p><u>G</u>: Self determination as relational, hence relational autonomy includes capacity for reflection on self motivation structure and ability to change motivation structure upon reflection. Also conceived as principled autonomy that linked obligations to rights, as viewed in turn by recipients (veteran patients) and actors (caregivers). Principled autonomy echoed Boszormenyi-Nagy’s relational ethics sense of fairness in balancing entitlements and obligations</p> |

Table 1 (Continued)

| | |
|--|---|
| | <p><u>RS:</u> Recognizes limited applicability of autonomy seen as individualistic self-governance free of personal limitations and outside interference in veterans' cases; considered veterans' autonomy in social structural and interpersonal context that qualified the term as "relational autonomy" that validated other ethical concerns and resource demands; (play metaphor outcome that portrays degree of ethical caregiving for each veteran)</p> |
| <p>Biopsychosocial and Psychosocial (Engel, 1977)</p> | <p><u>G:</u> Biomedical model did not include patient as person, medical care system required "consideration of biological, psychological, and social perspectives to provide effective care" (p 3). Psychosocial, used to describe all non-biological factors, in contrast to purely biological concerns.</p> <p><u>RS:</u> Veterans case documentation partly framed and categorized by biopsychosocial perspectives; primary focus on relational, psychosocial documentation</p> |
| <p>Care and Caregiving (Hollway, 2006; Tronto, 1993)</p> | <p><u>G:</u> Tronto's four phases of care, caring about (attentiveness), caring for (responsibility), care giving (competence), and care receiving (responsiveness); and Hollway's four kinds of care, interdependent care giving-receiving, can meet asymmetrical demands, capable of self care, and extension of care to larger issues (environment, animals, institutions, etc.)</p> <p><u>RS:</u> Inclusive of entire caregiving environment to include veteran patient and all formal and informal caregivers, concerned others, and relationally, their care activities and behaviors seeking to fulfill all eight categories listed.</p> |

Table 1 (Continued)

Relational Ethics
(Boszormenyi-Nagy, 1986;
Bergum & Dossetor, 2005)

G: Generally defined as perceived fairness of interpersonal give and take i.e., balancing entitlements and obligations; validates all involved persons; includes intergenerational impact; In healthcare also conceptualized as *third entity* between interacting persons, *relational* or *ethical* space that requires attention and nurturance

RS: Excluded intergenerational aspects, focused on fairness of give and take, nurturance of relational-ethical space; included concerted efforts to elicit, understand, and honor veteran patient's values and care desires; in emergent substantive theory it was essentially congruence between care provided and care desired.

Note. G: indicates a general definition from the source cited in "Key Terms" column.

RS: indicates research-specific definition as understood and used in this research

CHAPTER 2 – THEORETICAL FRAMEWORK

This research explored efforts to do the right thing by making the best ethical and moral choices, considering the physical and relational needs of caregivers and care recipient veterans, given social structural constraints of the Veterans Affairs Medical Center (VAMC). As detailed in chapter 3, grounded theory methodology (GTM) was used to examine documentation of interactions internal to the VAMC (study one) as well as documented interactions between medical center staff and veteran's family members (study two).

The theoretical framework that guided this research, social structural symbolic interaction, SSSI; (Stryker, 1968, 1980), was founded on conceptual constructs of symbolic interaction theory (Blumer, 1969; Mead, 1934). Although both Blumer and Stryker have often used the term symbolic interactionism in their writings, this study used the more contemporary term, symbolic interaction, throughout. As mentioned in chapter one, the chosen unit of analysis was caregiving relationships, with particular focus on relational meaning and decision making processes, in the context of a VAMC. This research and SSSI were influenced by three primary SI constructs.

Symbolic Interaction (SI) Constructs

First, individual and group meaning making processes place interpretation between stimulus and response. Among those deciding the meanings of caregiving circumstances are doctors, social workers, veterans, members of ethics committees, and veterans' significant others. Meanings are modified through awareness of veteran's status and rank, professional titles, diagnoses, and prognoses. For example, a doctor in a white coat with a stethoscope around her neck entering a veteran's hospital room will probably elicit acknowledgement of the knowledge and position this person represents. If the doctor then shakes hands with the veteran and says, "Hello sergeant, how are you today?" The sergeant will likely appreciate the acknowledgement of his rank and the concern with how he is feeling. These processes of interpretation in interaction go on constantly. Many interpretations may be automatic and unexamined but they continually influence our meaning making processes.

Second, meanings emerge from interaction, including internal thoughts and dialogues that inform our sense of self. The importance of individual self as an active social agent, that sense of self, arises through social interaction in roles such as war hero, fighter pilot, devoted husband or wife, colonel, and leader of troops. Once internalized these self concepts impact and motivate

behavior related to the role of hospitalized veteran. If the sergeant mentioned above is a retired air force chief master sergeant and the doctor is a much younger woman he may correct the doctor in a friendly manner and ask to be called *chief* rather than sergeant. After perhaps decades of being in a leadership position; being ill and in the hospital may make the chief feel uncomfortable and vulnerable. Perhaps the doctor is young but competent and confident in her ability to help this veteran with his medical problems. If so, rather than being defensive, she will likely smile and call him chief from then on. She could even note such personal and less diagnostic data in her daily case progress note as an addendum. These personal connections and observations are potential indicators of the engagement necessary for mutually respectful interaction (Bergum & Dossetor, 2005).

Third, meanings are modified by interaction with shared symbols. Social processes and self-society interactions impact meanings of continuity and change as once relatively independent, young, and strong veterans find themselves more dependent, older, more vulnerable, and in need of VA Medical Center care. Groups and individuals are shaped by social and cultural norms; the hierarchical nature of military life, the relative social status positions of doctor, nurse, minister, therapist, and others. Social structure evolves from daily interactions of individuals while in the military, in formal medical training institutions, and through specialized languages and other symbols that serve these social structures.

Continuing our hypothetical veteran's hospital example, even though the military culture is hierarchical and predominantly male, for many years social and cultural changes have rightly provided women the opportunity to advance in status and rank. If the doctor is military she outranks the sergeant. If she was raised in a family that taught younger members to respect older persons, there are, as always, ambiguous cultural and societal norms in play. Given the context of a veteran's healthcare facility, military rank would probably outweigh age differences. These inherent ambiguities of meaning are negotiated in relational processes that become more or less fair and balanced in give and take, providing an indicator of relational ethics (Boszormenyi-Nagy & Krasner, 1986; Boszormenyi-Nagy & Spark, 1973).

Social Structural Symbolic Interaction (SSSI) and Role Salience

This exploration of how ethics committee members, veterans, and other formal (paid, professional) and informal (friends, family, significant others) caregivers perceived, described, and documented issues related to resolving ethical dilemmas required intentional focus on

meaning making, subjective-objective processes, identities, roles, and salience of roles and relationships. Stryker's (1980) social structural symbolic interaction (SSSI), which emerged from key constructs of symbolic interaction (SI) theory and Mead's (1934) challenge us to understand the reciprocal relationship between self and society, provided that focus.

Stryker (2000) builds on the three primary SI constructs presented on pages 17-18, and provides more targeted theoretical guidance on how relational ethics functions in veterans care. His social structural concepts help clarify how structures' impact on self, and how self impacts behaviors and social structures. He refers to social structure as patterned regularities characteristic of human interaction, and makes the following statement:

Whatever may be true of the creative potential of persons in their interactions with one another, as a matter of empirical fact most of their interactions tend to be with the same or only slowly changing casts of others, and same sets of persons tend to be bound together or linked in interactional networks doing essentially the same things on a repetitive basis. Thus, the concepts of group, organization, community, etc., indicate aspects of social life in which subsets of persons are tied together in patterned interactions and are separated (at least with respect to those interactions) from other persons (Stryker, 2000, pp. 65-66).

The cast of caregivers at the VAMC changes slowly and there is the danger that veterans, as patient others, with certain medical conditions may come to be identified by the names of those conditions, leading to an unhealthy separation patterned around professional caregivers' perceptions. The various social structural networks of the VAMC may exert significant influence over the aforementioned principles of interpretation, interaction, and symbolic meaning modification.

Stryker also suggests awareness of how social structures create and reinforce roles that offer the potential to operationalize aspects of SI theory. Salience of role and self concept is influenced by role commitment, described as the degree to which relationships to specified sets of other persons depends on being a particular kind of person (Burke, 2003). This research explored how documented communication of social workers, nurses, doctors, veterans, and others demonstrated roles and role commitments. Doctors were the ones to deliver prognoses, social workers pursued communication with family members, nurses wrote more about body

care and made insightful observations from a close personal distance, and veterans communication, as reported, emphasized personal circumstances and relationships.

Degree of commitment to relationships is also defined as the cost of giving them up (Stryker, 1968). Role taking anticipates expectations and responses of others with whom one is involved in social interaction, while role making recognizes the ability to create and modify roles (Stryker, 1980). He explained that social structures strongly influence creation and validation of roles, which impacts identity and identity salience, influencing role relationship commitment. Commitment to and salience of relational ethics in role relationships as veterans, veteran patients, and caregivers were situated in this theoretical context.

Stryker adapted Mead's (1934) formula that *society shapes self which shapes social behavior*. Although appearing linear, this construct is essentially circular since it goes on and on, individuals are born into and shaped by society, then develop and shape society in turn, from generation to generation. The essential task posed by Mead (1934) was to understand this ongoing reciprocity between self and society. In this research the self is the veteran care recipient and various formal and informal caregivers. Society is the social reality of the systemic structures of the patient's family and the Veterans Affairs Medical Center (VAMC).

Stryker (1980) reframed Mead's (1934) formula as *commitment shapes identity salience, which shapes role choice behavior*. Again, the process is ongoing with role choice behavior shaping and impacting identity salience and so on ad infinitum. Stryker's emphasis on social structural influences, in this case the VAMC, on commitment and role choice behaviors will guide analysis of relational ethics in ethical dilemma resolution.

This researcher posed another reformulation of Mead's original formula as *commitment shapes relationship salience, which shapes ethical choice behavior*. Time invested in this research determined that commitment to the salience of relationship per se impacted the process of making ethical choices and resolving healthcare dilemmas. There was also a sense that this process continued on as ethical choices impacted different relationships' salience in reassessing agency roles as case circumstances shifted over time.

SI and SSSI key constructs were presented in Table 2. These constructs, along with definitions of relevant SI and SSSI theoretical concepts introduced in Table 3, were necessary to understand how theory guided aspects of data analysis, conceptual category creation, and the linking of concepts. The researcher's theoretical approach situated SSSI theory within the larger

context of SI theory and offered insights conducive to developing substantive relational ethics theory. In SI terms, society shaped the selves of caregivers and care recipient patients; and those selves shaped social, relational behavior in the context of the VAMC. In SSSI terms, role commitment shaped identity salience for veteran patients and caregivers, which in turn shaped role behaviors.

For example, the role behavior of ethics committee members, in cases where veteran's decision making capacity was compromised, expressed the desire and efforts made to identify someone from outside of the VAMC social structure i.e., someone from the informal caregiver system, to be involved in ethical resolutions. The salience of this outsider role, to act as an agent in the role of decision maker or durable power of attorney, provided the potential for collaboration with ethics committee members in decision making processes. This actually complicated the process, but helped provide an intentional and ethical balance to caregiving dilemma recommendations and resolutions, seeking to support the best interests of veteran care recipients.

Table 2

Research Relevant Social Structural and Symbolic Interaction Constructs

| Construct Sources | Key Constructs |
|---|--|
| American Pragmatist (George Mead) | <p><i>Society shapes self which shapes social behavior;</i> Self as both subject (“I”) & object (“Me”); “I” as immediate & present self; “Me” as historically-derived social self</p> |
| Three Primary SI Constructs (From Symbolic Interaction Theory) | <p>Individual & group meaning-making placing interpretation between stimulus & response; Meanings emerge from interaction; Meanings modified by interaction with shared symbols</p> |
| Social Structural SI (Sheldon Stryker) | <p>Emphasizes social structure that frames roles; Relationship between identity salience & role commitment; <i>Role commitment shapes identity salience which shapes role behavior;</i></p> <p>Identity salience hierarchy shaped by social structural norms and network size</p> |

Note. Table contents derived from Sheldon Stryker, *Symbolic Interaction: A Social Structural Version*, 2002, published by Pearson Education.

Social Structural Symbolic Interaction (SSSI) Theory and Caregiving Context

Whatever the context, according to Stryker and Burke (2000), identities emerge from internalized meanings of various roles. Identities are arranged in a hierarchy with more salient identities given priority. Roles also vary in terms of formality and informality as well as social position (LaRossa & Reitzes, 1993). For example, family members caring for veterans may go through several stages of reconstructing their committed relationships; transitioning from anticipation, then adapting to both formal and informal aspects of the caregiving role, and later modifying roles to be more congruent with their transformed identities (Benner & Gordon, 1996).

SSSI Theory and Relational Ethics

As discussed in chapter one, social interactions surrounding both formal and informal caregiver-care recipient relationships indicate the need for the relational ethic of mutual respect (Bergum & Dossetor, 2005) and balancing fairness of give and take (Van Heusden & Van Den Eerenbeemt, 1987). Interactions within the VAMC, between ethics committee members for example, are formal caregiving deliberations involving paid representatives of various disciplines and professions. Doctors, nurses, social workers, mental health providers, and other professionals collaborate in making important caregiving decisions.

SSSI theory has stated that the hierarchy of identity salience is shaped by social structural norms and network size. The ethics committee in this research consisted of 25 members; many of whom have been on the committee for a number of years. Besides the ethical and practice norms of their various disciplines, documentation indicated that collaborative decisions made in the role of ethics committee member gave considerable weight to their case recommendations, regardless of professional hierarchies. Observations and opinions from social workers, nurses, and doctors appeared to carry equal weight. There were no indications discovered in the research data of committee input being ignored by VAMC caregivers. In addition, the wishes of family members and significant others were given serious consideration and carried precedence in most cases.

Veterans, spouses, siblings, children, grandchildren etc., interacting with ethics committee members and other hospital staff were well received, even when their network size was as small as one dedicated child or spouse. Whether all formal caregiver voices seemed validated; and whether veteran's, family and other informal caregiver's voices were documented

in case deliberations were some of the more significant ethical questions considered in this study (Geerlings et al., 2005).

Addressing Symbolic Interaction Criticisms

The choice of SI to guide this research influenced implementation of the chosen grounded theory methodology. Awareness of potential weaknesses of SI theory can help avoid pitfalls in development of substantive theory in relational ethics. Fundamental criticisms of SI frameworks have been made (Gusfield, 2003; Harter, 1999). Gusfield (2003) made three criticisms. Only two of his concerns apply in this research. First, that the real world of action is complex and indeterminate so that structural arguments are inherently flawed.

As Pellegrino (1993) has noted, in spite of complexity ethical choices and timely recommendations are unavoidable in bioethics and medical care. Focus on relational aspects of ethical deliberations in this study did seem to help clarify this admittedly complex process. Just because certainty is unattainable, efforts to increase understanding incrementally should not be abandoned. Gusfield's second concern is that far too much is assumed, rather than studied, in observation of interactions creating meaning. SSSI provided theoretical guidance in this study. However, veteran files were approached with few assumptions or presuppositions about what they might divulge. The choice of case documentation data meant that if it was not documented it did not happen, as far as the researcher was concerned. The chosen grounded theory methodology, explained in chapter three, mandated constant connection with and immersion in the actual data. Both of these choices mitigated the possibility to assume anything not present in the data.

Harter (1999) observed that symbolic interaction theorists' emphasis on social processes in construction of the normative self ignored the possibility of interactions going awry. The author discussed four potential dangers of developing a self dependent on social processes: one, the possible integration of unfavorable opinions about self; two, inability to internalize others' opinions; three, potential conflict between socially-constructed multiple selves; and four, the promotion of behavior based on a falsely conceived self.

Harter's acknowledged the impact of SI processes. Therefore, his criticism of SI gone awry seemed more about the efficacy of the process and its outcomes rather than denying the potential impact. This awareness of possible negative outcomes was acknowledged and discovered in this research. As an example, integration of unfavorable self opinion was necessary

in the case of a pedophile, to honor more significant social and ethical considerations. The inability to internalize others' opinions could not be determined from the data in this study. The potential conflict between socially-constructed multiple selves was implied in the data but did not seem to significantly impact the functioning of any process participants. The concept of behavior based on a falsely conceived self was apparent in the data. There were a number of cases where veterans tended to overestimate their capacity for self care and independent living. However, awareness of those false self conceptions facilitated collaborative interventions on behalf of the veteran to reach a more appropriate level of autonomy. This concept emerged as one element of the resultant substantive theory.

Criticism that SI has ignored the emotional dimension of human behavior (Manis & Meltzer, 1978) is necessarily addressed in exploring challenges presented by ethical dilemmas in veteran's caregiving. The *looking glass self* posed by Cooley (1902) considers the observation made by Ralph Waldo Emerson in his poem *Astraea, the star maiden*, "Each to each a looking-glass, reflects his figure that doth pass." Cycles of dependence, interdependence, and eventual return to dependence, dying, and death as the eventual outcomes of illness and aging, may be reframed as our final developmental challenge. It is unlikely emotion will be absent when caregivers and care recipients face such vulnerable looking glass selves.

In this research, powerful caregiving examples such as giving up on hospital care to go home to die, suicidal and homicidal ideation, sudden occurrence of life threatening conditions, possibly contaminated blood transfusions, and profound mental health conditions implied significant emotional content.

Table 3 presents the definitions of SI and SSSI theoretical concepts relevant to the research. Research questions follow the table; then Chapter 3 details the research methodology.

Table 3

Definitions of Relevant SI and SSSI Theoretical Concepts

| Theoretical Concepts | Definitions |
|--|---|
| Symbolic Interaction (Blumer, 1969) | Three premises: 1) human beings act towards things on basis of meanings those things have for them; 2) meanings are derived from social, relational interaction; 3) meanings are modified by interpretive processes |
| Social Structural Symbolic Interaction (SSSI) (Stryker, 1980) | Eight descriptive statements: 1) behavior dependent on named and classified worldview; 2) classifications include designated roles that invoke behavioral expectations; 3) people act in social structural context conscious of roles; 4) people apply names and roles to themselves as well; 5) in interaction people name the situation, others, and themselves, and organize behavior around those designations; 6) behavior is product of role-making processes reshaped by interchange between actors involved; 7) ability to make (modify) rather than just play a role is impacted by surrounding social structures; 8) the degree to which roles can be made rather than just played determines potential for larger social structural change |
| <i>Remaining Table Concepts are Elements of SSSI Theory:</i> | |
| Role Commitment | Degree to which people's relationships are dependent upon being a particular kind of person within that network or group |
| Role Making | Idea that initial designations of self, setting, and other are modified and can even be discarded as interaction progresses |
| Identity, or Role Identity Salience | Discrete personal identities perceived as ordered into a salience hierarchy, roles higher in hierarchy are more salient; |

Table 3 (Continued)

| | |
|----------------------------|---|
| | probability of role being enacted defines identity salience |
| Role Taking | Taking standpoint of others, process that builds the self, anticipates responses by others, when developed as anticipation with respect to oneself, becomes part of self that Mead ^a called “Me”, when combined with “I,” representing more proactive, individual response to organized attitudes of others, as source of spontaneity and creativity, we become complete selves as a synthesis of “I” and “Me” |
| Salience Hierarchy | Identities or roles higher in the hierarchy more likely to be invoked in more situations, various role identities hold varying and sometimes changing positions in the hierarchy |
| Social Structural Position | Refers to socially recognized group of actors, serve to cue certain behaviors when person is placed in recognized group or category |

Note. Sources for table contents are H. Blumer, *Symbolic Interaction: Perspective and Method*, 1969, University of California Press and S. Stryker, *Symbolic Interaction: A Social Structural Version*, 1980, Pearson Education.

^aMead’s concepts of self from G. H. Mead, *Mind, Self, and Society: From the Standpoint of a Social Behaviorist*, 1934, University of Chicago Press.

Research Questions

Main Research Question: How does case documentation and documented processes of resolving ethical dilemmas in institutional healthcare for veterans reflect relational ethics?

Relational ethics, as defined in chapter one, were recorded perceptions, descriptions, and evaluations of fairness of give and take; and, nurturance of relational-ethical space through engagement and mutual respect that elicited, understood, and honored patients' values and care preferences, thereby doing the right thing in caregiving. The following study-specific questions for main studies one and two are presented in both general and theoretical frameworks terms:

Study 1, Veteran-Formal Caregiver Relations, as reflected in case documentation:

1. Who initiates requests for ethics committee consults and how do ethics committee members perceive, describe, and evaluate ethical dilemma consult requests?

In SI terms, how do ethical meanings emerge and become modified by interactions between formal caregivers and between formal caregivers and veterans?

2. Which ethics committee members participate in interdisciplinary communication regarding caregiving ethical dilemmas? How do members participate i.e., how does the process work?

In SSSI theoretical terms, how do social structural norms of the VAMC shape role/identity salience and hierarchies for veterans and formal caregivers?

3. How do committee member's role commitments impact ethical perspectives and care recommendations for doing the right thing?

In SSSI terms, how does role commitment shape identity salience and role behavior?

4. How do ethics committee members' perceptions of relational ethics affect efforts and recommendations for resolving ethical dilemmas in caregiving?

In SI terms, how do group meaning-making processes place interpretation between stimulus (ethics consult request) and response (recommendations)?

Study 2, Formal-Informal Caregiver Relations, as reflected in case documentation:

1. How do veteran family members and significant others perceive, describe, and evaluate ethical dilemmas?

In SI terms, how do ethical meanings emerge and become modified by interactions between formal and informal caregivers?

2. Which committee members and veteran's family members initiate and participate in family-institution communication regarding critical or late-life caregiving ethical dilemmas? How do they participate (i.e., how does the process work)?
In SSSI theoretical terms, how do social structural norms shape cultural and familial role/identity salience and hierarchies for formal and informal caregivers?
3. How do family members and significant others' role commitments impact ethical perspectives and care recommendations for doing the right thing?
In SSSI terms, how does role commitment shape identity salience and role behavior?
4. How do family members and significant others' perceptions of relational ethics affect advocacy efforts and congruence with VAMC staff and veteran patient care preferences in resolving ethical dilemmas in caregiving?
In SI terms, how do group meaning-making processes place interpretation between stimulus (veteran's critical or late-life caregiving ethical dilemma) and response (advocacy for, or disagreement with, others' recommendations)?

CHAPTER 3 - METHODOLOGY

Qualitative Approaches and Purposes

In brief, the research purpose was to develop substantive theory that would explain how aspects of relational ethics influenced resolution of dilemmas surrounding veterans' healthcare crises at a Veterans Affairs Medical Center. This researcher wanted to be able to tell a compelling, reality-based, explanatory story of that process.

“Our assumptions, values, feelings, and histories shape the scholarship we propose...” (Allen, 2000, p. 14), including our choice of methodology. In a summer 2006 qualitative research course I first understood and was attracted to the fact that the qualitative process of inquiry was both an art and a science (Rossman & Rallis, 2003). I was drawn to this process that called for me to become an instrument of learning and interpretation with the goal of improving some social circumstance. I later learned that to become a good qualitative researcher required creativity as well as analytic skill, passion in partnership with reason, feeling as well as thought, and the ability to tell a valid story that both informs and stimulates the reader (Daly, 2007).

When the impetus to understand and interpret relational and ethical aspects of how veterans' healthcare crises are resolved and how that process is documented, qualitative methodology was my first choice. Given the nature of the phenomenon, and my conceptual preferences, the specific qualitative approach chosen was grounded theory methodology.

Researcher Conceptual Preferences

Adequate development and presentation of a qualitative research should provide the reader with a clear view of how the researcher is conceptually positioned in theoretical and methodological choices (Daly, 2007). My theoretical stance was explained in chapter two. My choice of grounded theory methodology (GTM) for this research derived from specific life experiences and conceptual preferences.

My conceptual and methodological preferences were guided by principles that, as a marriage and family therapist, valued interpersonal relations and meaning-making processes. The research phenomenon, involving ethical issues in veteran's caregiving, engaged my passion as a Vietnam era veteran. The purpose of the study, to explore aspects of relational ethics in efforts to resolve ethical dilemmas and ground substantive theory in documented reality, fed my ship captain's desire to do research with practical implications. Initial research questions that sought

to understand how formal and informal caregivers and veterans navigate complex relationships in seeking to resolve healthcare dilemmas gave me the motivation to do the work.

These preferences positioned my chosen methodology in conceptual context (Daly, 2007). The Table 4 framework on the next page (Daly, 2007) presented conceptual preferences along with fundamental principles and processes guiding this research. Epistemological subjectivism emphasized meaning making processes, i.e. constructions, as residing in the mind of the knower. Subjectivism questioned relational separation between knower and known. Research objectivity is worth striving for but there is an inherent dilemma, researcher as research instrument, interprets and constructs conclusions. Claims of objectivity are not made. However, the research process is made as transparent as possible so validity can be evaluated by readers.

The social constructionist proposes that all reality is constructed. Meanings are constructed in interaction, or relationship. Interpretive processes are impacted by shared meanings, cultural perspectives, and other socially accessible, experienced realities (Daly, 2007). Symbolic interaction perspectives were presented in Chapter 2; Grounded Theory Methodology is introduced next, along with an explanation of case study analysis.

Table 4

Researcher Conceptual Preferences

| Preferences | Principles and Processes |
|------------------------------------|---|
| Epistemological Subjectivism | <p>Meaning-making and interactional processes; e.g. veteran's health crisis defined as ethical dilemma and ethics committee meeting, consultation with veterans and others for resolution recommendations.</p> <p>Healthcare provision for veterans; e.g. rationales behind shift from attempts to cure to comfort care.</p> <p>Subjective interpretation of setting; e.g. whether veteran perceives medical center staff as acting in his or her best interests.</p> |
| Social Constructionist Paradigm | <p>Interpretive process shaped by shared-meanings; meaning-making process as interactive, i.e. relational. How roles, goals, social commitments impact communication and interaction; e.g. veteran's strengths, in the role of patient, may be recognized or not; treatment goals may be perceived by some as conflicted; and commitments to healing may override other relational considerations.</p> <p>Nature of ethical processes in decision & meaning-making in caregiving; e.g. principle-based resolutions may include relational considerations and social context or not.</p> |
| Symbolic Interaction Theory | <p>Symbolic interaction & social structural symbolic interaction (see Tables 2 and 3 in chapter 2). Applied at formal & formal-informal caregiver interactions levels, i.e. internal to the VAMC and between VAMC and veterans' significant others.</p> |
| Grounded Theory Methodology | <p>Open coding and concept creation.</p> <p>Constant conceptual comparison.</p> |

Table 4 (Continued)

Simultaneous collection, analysis, and interpretation processes.
Emergent design, theoretical sampling, seeks conceptual
saturation.
Substantive theory as outcome.

Case Study & Document Analysis Methods
Coding, category creation, conceptual links and comparisons of computerized archived data of 25 ethics committee cases; data management aided by *ATLAS.ti* qualitative software.

Note. Table conceptual preference structure derived from *Qualitative Methods for Family Studies and Human Development*, by K. J. Daly, 2007, Sage Pubs, p. 166; adapted from *The Foundations of Social Research: Meaning and Perspective in the Research Process*, by M. Crotty, 1998, Sage Pubs.

Grounded Theory Methodology (GTM)

Qualitative approaches and purposes and researcher conceptual preferences explained the compatibility of subjectivisms' emphasis on relational meaning making, constructionist perceptions of interpretive processes, and previously presented social structural symbolic interaction theory. Grounded theory methodology (GTM) provided a means to apply researcher conceptual preferences to data analysis. The origins of GTM follow.

Origins, Glaser and Strauss. Grounded theory methodology (GTM), also called grounded theory methods, was developed by Barney Glaser and Anselm Strauss (LaRossa, 2005) from their studies of hospital deaths in the Bay area of San Francisco in the 1960s (Glaser & Strauss, 1965, 1968). As with the intent of this research, their publication *Awareness of Dying* in 1965 developed substantive social interaction theory in a medical setting, "grounded in research on one particular substantive area" (Glaser & Strauss, 1965, p. 275), in their case, dying. They focused on the consequences of who did and did not know or recognize that the patient was dying. Although their discussion of social interactions had relational implications, their research did not deal with relational ethics issues.

Continuation of their emergent research design, *Time for Dying*, published in 1968, added temporal aspects of dying to their substantive theory. They called for comprehensive systemic reform and made four major recommendations, none of which addressed relationship issues.

After discussing their recommendations they stated, "...we urge readers to think of additional ones..." (Glaser & Strauss, 1968, p. 259). Using grounded theory methodology (GTM), as developed from these two seminal studies, and enhanced by numerous scholars including LaRossa and Daly introduced next, this study seeks to generate substantive theory with the potential to describe, explain, and make recommendations to improve relational ethics and resolution of ethical dilemmas in caregiving.

LaRossa's principles and Daly's stages. Now that use of GTM has been conceptually positioned, the following presents key principles (LaRossa, 2005) and process stages (Daly, 2007) that guided application of GTM methodology in the study. LaRossa emphasizes sensitivity to process and suggests three major phases of research and analysis. He stresses the non-linear nature of GTM and general emphasis on induction but agrees with Daly that both inductive and deductive methods are at work. According to Daly (2007) two fundamental principles guide grounded theory methodology (GTM), emergent design and emphasis on theory generation. Daly emphasizes a recursive cycle of inductive and deductive reasoning that goes through four, somewhat overlapping, stages. This iterative process goes back and forth from research data analysis to initial and emerging theoretical frameworks. A combination of LaRossa's five principles and Daly's four stages are shown in Table 5.

LaRossa's five principles provided insight into conceptual processes underlying procedures delineated in Daly's four stages. As GTM was applied to data analysis in this research, the procedures of open coding, category creation, axial coding, and theory formation, were informed by LaRossa's principles. Recognition of the centrality of language, and theoretical reflection, as conceptual comparison of interrelated propositions, ultimately led to the choice of one category, relational autonomy, as central to the successful development of substantive theory in relational ethics in caregiving for veterans.

Table 5

Grounded Theory Methods – Guiding Principles and Process Stages

| GTM Scholar Perspectives | Key Principles and Processes |
|--------------------------|--|
| Ralph LaRossa (2005) | <p>Methodologically Condensed GTM</p> <p>Five Principles^a:</p> <ol style="list-style-type: none"> 1) Language central to social life; 2) Word indicators form GTM derived theory; 3) Explanation built on conceptual comparison; 4) Theories are sets of interrelated propositions; 5) Choice of one category as central to theory |
| Kerry J. Daly (2007) | <p>Emergent Design & Theory Generation</p> <p>Four Stages^b:</p> <ol style="list-style-type: none"> 1) Open coding and creation of concepts; 2) Creating Categories; 3) Making linkages in data (axial coding); 4) Creating theoretical story line; choosing core category |

Note. Regarding table contents, for origins of GTM principles and processes see B. Glaser & A. Strauss, *Awareness of Dying*, 1965, and *Time for Dying*, 1968, Aldine Pubs. Also, A. Strauss & J. Corbin, *J. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 1998, Sage Pubs.

^aFive principles from “Grounded Theory Methods and Qualitative Family Research,” by R. LaRossa, 2005, *Journal of Marriage and Family*, Vol. 67, pp. 837-857.

^bFour Stages from *Qualitative Methods for Family Studies and Human Development*, by K. J. Daly, 2007, Sage Publications, pp. 230-241.

The first two of LaRossa’s principles are congruent with symbolic interaction theory guiding the research; that meaning making, interpretation, and meaning modification take place in interaction. In this case, documented interactions internal to the VAMC, as well as those between medical center staff and veterans’ significant others, provide and modify meanings

related to ethical dilemmas. Principle one, language as central to social life, leads to analysis of the interactive language and meaning making documented in the VAMC *Computerized Patient Record System* (CPRS). Analysis of psychosocial and relational language aspects reveals salient ethical content. Principle two, word indicators from GTM theory, leads to emphasis on line-by-line coding of research-relevant documentation, memo writing, subsequent category creation and axial coding identifying conceptual linkages.

The remaining three principles are upheld in Daly's four stage approach. Principle three specifies that explanation be built on conceptual comparison. Constant comparison is essential to GTM and specified in Daly's first three stages; it is also implied as necessary during final conceptual comparisons in stage four. Principle four states that theories need to be understood as sets of interrelated propositions. Development of substantive theory in Daly's stage four creates the story line at the highest level of abstraction warranted by study findings. The resultant substantive theory and story line addresses interrelated propositions relevant to the relational ethics phenomenon. It will have also met principle five, choice of a central category, as part of the process of telling the story the data has told focused on a core category.

LaRossa's (2005) grounded theory methods (GTM) approach emphasizes theory development as a major criterion for assessing qualitative research. He describes the five principles as linchpins of GTM: centrality of language; reciprocity between words on the page and theories in the mind; need for empirical and conceptual comparisons; theory as a set of interrelated propositions not interrelated variables; and choice of a particular variable, or story line, empowers grounded theoretical analysis and writing. LaRossa uses the term variable as synonymous with category. This research uses the GTM term category rather than variable.

LaRossa (2005) makes a strong argument for starting with a shift from an explication of concepts to the development of categories. The process is to theoretically saturate a concept so that it becomes a category. There may be several conceptual elements at numerous levels to be accounted for under the umbrella of a category. He explains that open or line-by-line coding is at the heart of the GTM approach; that process and interaction are better framed under axial coding; and that the difference between open and axial coding comes down to the difference between a topology and a theory. In open coding the researcher is developing categories. In axial coding the relationship between and among categories is emphasized. The researcher must eventually decide upon the main story, leading to the need for selective coding; using GTM can effectively

craft theoretical stories. Daly (2007) agrees with LaRossa, placing emphasis on initial aspects of open coding and concept creation.

Daly (2007) presents two related paradoxes that make the effective use of grounded theory methods challenging. First, the term “grounded” implies being concrete, tangible, and rooted in reality, while “theory” is inherently abstract, propositional, and seeks to generalize, at least to some degree, beyond the substantive area under investigation. Second, the fundamental principle of emergent design suggests, as does Charmaz (2003), that the approach should be initiated with as little theoretical bias and preconception as possible.

Implementing Grounded Theory Methodology. In the world of social research, and in this study, prior knowledge and a theoretical framework did guide what could otherwise, in the opinion of this researcher, be too random a process to implement effectively. A major challenge in this, as in all GTM research, was to balance the tension inherent in the paradoxes presented, to be focused and intentional in remaining grounded in the data, while simultaneously using the self as scholar to develop a valid and useful theoretical story.

GTM implementation stages and procedures used in this research are summarized in Table 6 as condensed from Daly (2007). After presentation of the main study population and three-phase research strategy, the analytic procedures in Table 6 were implemented in all three phases of the study.

Table 6

GTM Stages and Procedures

| Stage of Analysis | Analytic Procedures |
|--|--|
| Stage 1: Open up the Data | Fracture the data into segments; Create code names Code meaningful data line-by-line Common indicators become concepts Naming process forwards reflection process |
| Stage 2: Create Categories | Build on concepts from Stage 1 Further abstract data and create categories Identify properties/characteristics of categories Identify dimensions of properties Reach point of greatest complexity |
| Stage 3: Link Data and do Axial Coding | Reassemble data fractured in stages 1 and 2 Identify core axes on which categories are built Examine relationships within and between categories Seek theoretical saturation for each category Expand and combine categories as appropriate Consider process and interaction aspects Reduce, refine, and link categories |
| Stage 4: Create Theoretical Storyline | Identify core category Selectively code to integrate and refine theory Highlight key elements and salient features Seek explanation of processes and relationships Tell story data has told Generate substantive theory |

Note. For origins of GTM principles and processes see B. Glaser & A. Strauss, *Awareness of Dying*, 1965, and *Time for Dying*, 1968, Aldine Pubs. Also, A. Strauss & J. Corbin, *J. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 1998, Sage. Table stages and procedures derived from *Qualitative Methods for Family Studies and Human Development*, by K. J. Daly, 2007, Sage, pp. 230-237.

Research population identification and data access. Major challenges in implementing GTM methodology and conducting this research included identifying the research population, CPRS access, selecting and setting appropriate limits on CPRS data inclusion, evaluating internal research validity, and assessing congruence of resultant substantive theory with VAMC reality. None of these challenges could have been met without the expertise, support, and mentoring of Dr. Kye Kim, principle investigator at the VAMC for this Veteran's Health Administration (VHA) ethics study. Dr. Kim is Director of the Dementia Unit and Memory Disorder Clinics at the VAMC and Professor of Clinical Psychiatric Medicine at the University of Virginia. He has been an employee of the VA for 22 years and an ethics committee member for 10 years.

The VAMC uses a *Computerized Patient Record System* (CPRS) to document veteran's cases and archive thousands upon thousands of daily progress notes, assessments, case histories, reports, consultations, discharge summaries, etc. The CPRS provides links to other VAMC facilities and services utilized by veterans with the potential to reach hundreds of thousands of case files across the nation. All case documentation in this study was limited to the VAMC site where the CPRS data files were accessed.

Dr. Kim's involvement as VAMC principle investigator provided CPRS access. As a member of the ethics committee he identified the relevant population of VAMC veteran cases (N=25). His expertise evaluated and confirmed identification of relevant data sources, data selection, and sampling. In weekly meetings he monitored data collection and provided a member check on emerging categories, concepts, and conceptual relationships. Finally, he confirmed the resultant theory as congruent with day-to-day VAMC caregiving reality. Ethically speaking, Dr. Kim respected the exploratory nature of this research and never sought to redirect or unduly influence the researcher's journey of discovery. In fact, he consistently encouraged me to focus on data content and base my findings on that alone.

The population in this research represented all veteran inpatient cases, between October 2003 and January 2008, which required the involvement of the VAMC ad hoc ethics committee. VAMC ethics committee consults were precipitated by veteran's physical and mental health crises and care provision decision dilemmas. All three phases of the research utilized data limited to this population. Veteran's cases were numbered randomly from number two to 26. Observations, findings, and discussion used designated case numbers throughout the research presentation to maintain confidentiality.

Substantive theory quality factors. The ultimate research goal was production of a substantive theory of interpersonal relational ethics leading to ethical dilemma resolutions in institutional caregiving for veterans. Quality and validity factors that further guided substantive theory development followed suggestions by Daly (2007) presented in Table 7. The resultant relational ethics substantive theory was evaluated in chapter 6 based on the presented quality factors.

Table 7

Qualities of a Good Substantive Theory

| Quality Factor | Evidence |
|-----------------------------------|--|
| Linked to & grounded in data | Connects to everyday VAMC staff, veterans, others' reality |
| Saturated | Categories show range of properties with similarity and variability, properties have dimensions |
| Plausible | Plausible in relation to everyday reality, passes the phenomenological test of live experience |
| Explanatory | Provides explanation of ethical processes and relationships beyond mere description |
| Integrated | Category relationships and linkages are clear and comprehensible |
| Parsimonious | Focused and simple enough to provide clarity of complex phenomenon of relational ethics |
| Delimited | Presents compelling story about phenomenon of interest |
| Generative | Raises new questions and curiosity, not definitive approach |
| Comprehensive | Includes enough contradictions and complexity of the real life phenomenon, avoids oversimplification |
| Possible linkage to formal theory | Potential to theorize about more formal, generic social, ethical, and relational interactions |

Note. Table Contents adapted from *Qualitative Methods for Family Studies and Human Development*, by K. J. Daly, 2007, Sage, pp. 237-238.

Use of qualitative software – ATLAS.ti. Recent discussion about the use of software to help conduct qualitative research coined the term Computer Assisted Qualitative Data Analysis or CAQDAS to describe the variety of tools and programs available (Lewins & Silver, 2007). Of these tools, *ATLAS.ti* was selected to assist with analysis in this research (Scientific Software Development, 2004). The software is described in the *User's Guide and Reference* as a “powerful workbench” environment that provides a “systemic approach” to managing large amounts of “unstructured data”; and promises to help with the exploration of “complex phenomena” (2004, p. 2). This researcher confirms those claims were validated in conducting this research. *ATLAS.ti* helped to keep track of over 100 memos, 300 plus codes, along with thousands of quotations and allowed for complex data searches and queries that facilitated discovering conceptual relationships and theory generation.

Research Population – 25 Cases

Identification of research population. As explained in the *Challenges to Implementing GTM Methodology* section, the research population consisted of 25 veteran ethics committee consult cases. Dr. Kim, as Director of the Dementia Unit and Memory Disorder Clinics and member of the VAMC ethics committee, identified the relevant population of VAMC veteran cases, as described on page 39.

Part of the inherent selectivity of the study population was that all of the veterans had attained eligibility to receive medical care from the Department of Veterans Affairs. The 2008 edition of *Federal Benefits for Veterans and Dependents*, a 140-page booklet, explained that determining eligibility for care was a two-step process (Department of Veterans Affairs [VA], 2008). Step one involved the VA evaluating the character of the veteran's discharge from military service; whether the discharge was honorable, which qualified for care, or some other type of discharge, which may or may not qualify. The VA also considered length of active duty military service. In step two, the VA determined whether the veteran qualified for one of eight priority healthcare groups (VA, 2008).

The eight-group care system gives the highest priority to group one veterans who are 50 percent or more disabled or unemployable due to service-connected incidents or conditions; group two with service-connected ratings at 30 to 40 percent; group three at 10 to 20 percent; group four are veterans who are housebound or catastrophically disabled; group five veterans have VA pension benefits or meet net worth and other financial means tests; group six are World

War I and Gulf War veterans with care needs related to service-connected exposure to damaging materials or are receiving disability compensation; group seven are those meeting a geographically-based income threshold; and, group eight are veterans enrolled prior to January 17, 2003 who agree to pay co-pays for health services (VA, 2008, pp. 2-3)

Once determined eligible for one of the priority groups, the veteran was considered to be enrolled in the VA system. All veterans in the study population were enrolled in the VA healthcare system. In order to maintain research transparency, note that the researcher had been enrolled for VA health services in another state since 2001 and in April 2008 successfully transferred that enrollment to the VA Medical Center where this research took place.

Demographics and description of population. Basic demographic and descriptive data provided by CPRS case documentation is presented in Table 8. Veteran patients in the research population ranged in age from 45 to 88 years old, at the time of the ethics committee referral date (ECRD) for each case.

Forty percent (10 of the veterans) were adults (45-64 years old); 20 percent (5 veterans) were in the young-old age category (65-74 years old); 32 percent (8 veterans) were in the old-old age category (75-84 years old); and eight percent (2 veterans) were in the oldest-old category (85 years old or older). The mean age was 67.44 years old, with a standard deviation of 12.563 years. At the time of this research 72 percent, or 18 of the veterans, were deceased.

Marital status data indicated that 44 percent (11 veterans) were married; 36 percent (9 veterans) had never married; 12 percent (3 veterans) were divorced; and eight percent (2 veterans) were widowers. Racially, 84 percent (21 veterans) were Caucasian Non-Hispanics and 16 percent (4 veterans) were African American or Black.

Veteran's reported the following religious affiliations, 28 percent (7 veterans) as Baptist; 24 percent (6 veterans) as Protestant; eight percent (2 veterans) as Jewish; eight percent (2 veterans) as Catholic; five percent, or one veteran, reported affiliation with each of Brethren, Episcopalian, Jehovah's Witness, and Presbyterian. The remaining four veterans, or 16 percent, reported no religious preference.

Veteran's military service demographics were 32 percent (8 veterans) Army; 32 percent (8 veterans) Navy; 28 percent (7 veterans) Air Force; five percent (1 veteran) Marine Corps; and one veteran who served in both the Army and Navy. And, for service era, twenty percent (5 veterans) served during World War II; 16 percent (4 veterans) during the Korean Conflict; four

percent (1 veteran) in the Post-Korean era; 44 percent (11 veterans) during the Vietnam War; and 16 percent (4 veterans) during the Post-Vietnam era.

Based on inpatient statistics provided by the administrative offices, through Dr. Kye Kim, the number of inpatients for the fiscal year beginning October 1, 2006 and ending September 31, 2007 was 4,224 veterans. The research timeframe, referenced to ethics committee referral dates (ECRD), was from October 8, 2003 to January 9, 2008, or four years and three months.

Therefore, the research population of 25 veterans, using an estimated total inpatient population of 17,952 (4,224 x 4.25) for the research time period, represented 0.139 percent of the VAMC inpatient population; or, one of every 718 cases. As explained on page 39, these veteran cases were unique in requiring ethics committee consultation. In that sense they were outliers in the general population. The vast majority of cases precipitated no request for ethics committee involvement.

Table 8

Research Population Demographics (N=25)

| Case | Age ^a | Military Branch | Service Era | Race ^b | Religion ^c | Marital Status ^d |
|------|------------------|-----------------|--------------|-------------------|-----------------------|-----------------------------|
| 2 | 88 | Army | WWII | White | Unknown | Widowed |
| 3 | 81 | Army | WWII | White | Unknown | Married |
| 4 | 53 | Navy | Vietnam | White | Baptist | Never Mar |
| 5 | 50 | Air Force | Vietnam | White | Baptist | Never Mar |
| 6 | 45 | Air Force | Post Vietnam | White | Jewish | Never Mar |
| 7 | 75 | Air Force | Vietnam | White | Baptist | Married |
| 8 | 75 | Navy | Vietnam | White | Protestant | Married |
| 9 | 62 | Army-Navy | Post Vietnam | White | Unknown | Married |
| 10 | 59 | Army | Vietnam | White | Unknown | Married |
| 11 | 48 | Navy | Post Vietnam | White | Jehov. Witness | Married |
| 12 | 71 | Army | Korea | White | Brethren | Never Mar |
| 13 | 74 | Air Force | Vietnam | White | Catholic | Married |
| 14 | 86 | Army | WWII | White | Catholic | Married |
| 15 | 76 | Air Force | WWII | White | Protestant | Divorced |
| 16 | 58 | Navy | Vietnam | White | Baptist | Divorced |

| | | Table 8 | (Continued) | | | |
|----|----|-----------|--------------|---------------|--------------|-----------|
| 17 | 73 | Air Force | Vietnam | White | Protestant | Married |
| 18 | 75 | Navy | Korea | African Amer. | Protestant | Never Mar |
| 19 | 69 | Navy | Post Korea | White | Presbyterian | Never Mar |
| 20 | 58 | Navy | Vietnam | White | Episcopalian | Married |
| 21 | 47 | Army | Post Vietnam | White | Baptist | Never Mar |
| 22 | 58 | Marines | Vietnam | White | Jewish | Never Mar |
| 23 | 78 | Army | WWII | African Amer. | Baptist | Married |
| 24 | 74 | Army | Korea | African Amer. | Protestant | Never Mar |
| 25 | 74 | Air Force | Korea | African Amer. | Baptist | Widowed |
| 26 | 75 | Navy | Vietnam | White | Protestant | Divorced |

Note. All veterans in the patient population were male.

^aAge is indicated at the time of the documented ethics consult for the case.

^bRace documentation for Caucasians was listed as White, Non-Hispanic in case files; African Amer., indicates Black or African American veteran.

^cReligion entry of “Unknown” was documented as unknown or unreported.

^dMarital Status listed as “Never Mar” indicates veteran was never married.

Table 9

Research Population Demographic Percentages (N=25)

| Demographic Information | Number of Veterans | Percent of Total |
|-------------------------|--------------------|------------------|
| Military Branch | | |
| Army | 8 | 32% |
| Navy | 8 | 32% |
| Air Force | 7 | 28% |
| Marines | 1 | 4% |
| Army and Navy | 1 | 4% |

Table 9 (Continued)

| | | |
|-----------------|----|-----|
| Service Era | 5 | 20% |
| World War II | 4 | 16% |
| Korean Conflict | 1 | 4% |
| Post-Korea | 11 | 44% |
| Vietnam | 4 | 16% |
| Post-Vietnam | | |

| | | |
|----------------|----|-----|
| Marital Status | | |
| Married | 11 | 44% |
| Never Married | 9 | 36% |
| Divorced | 3 | 12% |
| Widower | 2 | 8% |

Three-Phase GTM Research Process

Institutional Review Board approvals were applied for and received from both the Department of Veterans Affairs and Virginia Tech's Office of Compliance (see Appendices A and B).

Throughout the three-phase research process, veterans were referred to only by their case numbers, i.e. case 2 = C2, case 5 = C5, case 20 = C20, and so on, to maintain confidentiality. Based on discussions with Dr. Kim and VA confidentiality concerns all staff identifying information was deleted as well.

A serious concern was whether or not case documentation would support the purpose of the research. For that reason, in collaboration with my dissertation committee chair and principal investigator, Dr. Jay Mancini, a three-phase research strategy was implemented that included a phase one feasibility study and phase two pilot study prior to conducting the two main studies.

The timeline for the entire research process was as follows:

Three Phase Research Timeline

| <u>EVENT</u> | <u>TIMING</u> |
|--|-------------------------------------|
| VAMC Ethics Committee Meeting (Meeting Attendance and Veteran's Bedside Visit as Initial Impetus for Study) | June '07 |
| Phase One - Feasibility Study (Sample Data from 25 Cases, 55 Pages of Data) | November '07- January '08 |
| Dissertation Proposal Development Dissertation Proposal Defense | December '07-April '08 April '08 |
| Phase Two - VAMC Pilot Study (Selected Data, 106 Pages from 2 Cases, CPRS Data Access Began 3/13/08) | March-April '08 |
| Phase Three – Two Main Studies Main Study One Main Study Two Data Collection and Analysis (Selected Data, 1439 Pages from 25 Cases, CPRS Data Access Dates, 3/13 – 8/13/08) | April-June '08 June-August '08 |
| Analysis & Dissertation Completion | April-October '08 |
| Dissertation Defense | October '08 |

Phase One – Feasibility Study – 25 Cases

Now that the research population has been presented and described it is important to note that during the Phase One Feasibility Study the researcher did not yet have access to the *Computerized Patient Record System (CPRS)*. The Feasibility Study began when I gained indirect access to CPRS case data in November of 2007 and was completed in January 2008. The study's intent was to get an initial impression, to the satisfaction of the researcher and primary investigators, whether or not the data would support the research. Initial phase one analysis supported moving forward with phase two.

Data sample and methods. Dr. Kye Kim gave me copies of ethics committee consult progress notes for all 24 cases requiring ethics committee involvement from October of 2003 through November 2007. In January of 2008 Dr. Kim provided notes on an additional ethics consult for a total of 25 cases. These copies of case documentation consisted of 55 total pages of data for the 25-case population. All veteran and staff identifying information had been deleted from the data.

Feasibility Study methodology included stage one and two procedures from Table 4 in an initial GTM analysis of this limited data set from each of the 25 veterans' case files. The source data was one to three pages of hard copy progress notes of ethics consults for each of the 25 cases requiring ethics committee involvement. As a ten-year member of the ethics committee, Dr. Kim had knowledge of and access to these case files and provided copies of the consults to me. This initial data sample included; list of disciplines participating on the committee, reasons an ethics consult was requested, member's responses to requests for consults, member observations, and committee recommendations.

Ethics committee members involved in these ethical deliberations included the following professions, disciplines, and participants: administrators, attending and resident physicians, medical and mental health consultants, ministers and chaplains, nurses, nurse supervisors, psychiatrists, social workers, case managers, and in one case, myself as a gerontology practicum student. Family members were seldom directly involved in the process but there was a conscious effort by hospital staff to include, document, and advocate for family perspectives, concerns, and wishes in their deliberations.

Scholars using GTM strongly recommend that management of emergent design requires taking extensive notes throughout the research process in the form of memos (Daly, 2007;

LaRossa, 2005; Strauss & Corbin, 1998). Memos serve to shape research direction and record key decisions and insights regarding methodology and theory development. For example, I wrote the first memo on this data set on June 27, 2007 when I attended an ethics committee meeting as a graduate practicum student. Later that afternoon I visited the veteran's bedside with a committee member and observed an elderly man who had been bed bound and on life support, off and on, for almost one year. That bedside visit, as reflected in my memo helped precipitate this research and motivated my desire to understand how the VAMC ethics committee resolves ethical dilemmas related to caregiving decisions for veterans who find themselves in such complex and challenging circumstances. And, how they and others document i.e., tell that story.

Data analysis. Analysis of the limited data sample of ethics committee progress notes for the 25 cases produced four initial categories with a number of concepts related to each category. Stage 1 open coding began as a list or typology derived from line-by-line coding, 49 pages of notes, and memos related to the cases. After comparing and contrasting various notes, codes, and memos, several levels of categories and concepts emerged as stage one and two analysis proceeded.

Stage one and two followed analytic procedures previously presented in Table 4:

| | |
|---------------------------|--|
| Stage 1: Open up the Data | <ul style="list-style-type: none"> Fracture the data into segments Create code names Code meaningful data line-by-line Common indicators become concepts Naming process forwards reflection process |
|---------------------------|--|

| | |
|----------------------------|---|
| Stage 2: Create Categories | <ul style="list-style-type: none"> Build on concepts from Stage 1 Further abstract data and create categories Identify properties/characteristics of categories Identify dimensions of properties Reach point of greatest complexity |
|----------------------------|---|

Briefly, the feasibility study started by opening up the data and coding what seemed most meaningful. Considering the focus on ethical dilemma resolution, coding began with the ethical dilemma or reason for the consult and committee recommendations for resolution.

A sampling of case documentation for those two items follows. Explanatory comments are presented in parenthetical italicized format (*italics*).

C4 reason for consult:

Reason for Referral: 53 y/o with decision making capacity, but severe medical illnesses and disabilities, wants more autonomy, often requests AMA (*Against Medical Advice*) discharge, but staff and family feel he cannot take care of himself. We would like Ethics committee's assistance in deciding what to do. Can we discharge this patient independently if he wants to leave? If we cannot discharge this patient can we require him to sleep in a room without access to water to prevent him drinking too much?

C4 ethics team recommendations:

1) Recommend neuro-psych testing, 2) step-wise progression to independent living, 3) contact district counsel for guidance regarding patient desires discharge when questions arise regarding his decision making capacity.

Coding for these entries included, poor prognosis, seeks autonomy, AMA (*Against Medical Advice*), ADL (*Activities of Daily Living*) capacity, family involvement, family opinion, and behavior control issue. It was notable that in spite of severe medical problems the committee still supported the veteran's desire for more autonomy recommending progression to independent living.

C13 Reason for consult:

This case was referred by Ms. Cxxx on 7/26/05 who is a RN on Renal Unit. Reportedly, the patient expressed his wish to discontinue renal dialysis on 7/25/05 while he was receiving his regular dialysis. It's reported that this was not the first time that he expressed the same wish. This was also confirmed by his wife of 45 years. The question asked by Ms. Cxxx to the committee was whether she should honor his wish while the patient's wife wishes him to continue with the Tx (*treatment*).

C13 ethics team recommendations:

1) There are some conflicting observations on his mental status. Per dialysis staff, he can be mentally clear although he is very tired most of the time. His wife reports that he is

often "in and out." We need to establish his mental capacity. He may have underlying cognitive dysfunction and additionally even delirium due to his complicated medical conditions. We would recommend consult to Psychiatry for evaluation.

2) There is also a question about possibly undertreated depression. Although he has been on citalopram, there has been no documentation about the Tx (*treatment*) response. His wife states his mood has been always the same. We may want to optimize his depression if possible for the sake of his benefit.

3) Is his hearing impaired? His wife claims that he does have hearing difficulty. This needs to be clarified.

4) Regardless whether he has a mental capacity or not, the clinical team should work with his family (wife and two sons). Also, make it sure that his spiritual needs are met. His wife reports that she has not observed much interaction between him and his priest. We should provide an assistive device to improve his communication with his priest (for instance, pocket talker).

Coding in this case included, nurse referral, 45 year marriage, veteran's wishes, wife's wishes, mental capacity, co-morbidity (physical and mental problems), psychiatric evaluation, depression, for veterans benefit, hearing impairment, family involved, spiritual needs, and communication assist device.

As coding continued, some of the first common indicators or code groups were medical condition, mental capacity/condition, family involvement, advance directives, and power of attorney. These common code groupings produced a typology of indicators in the feasibility data for the 25 cases as follows:

- Co-morbidity of mental health issues combined with physiological problems
- Importance of advance directives such as "Do Not Resuscitate" (DNR)
- Family involvement, motives, commitment to caregiving role
- Patient/Veteran autonomy
- Determining and honoring patient/veteran late life care wishes
- Legal aspects such as power of attorney or guardianship
- Prognoses of physiological and mental health
- Presence and course of dementia
- Management of distribution of psychoactive medications

- Actions taken by family or patient against medical advice
- Reasons for referral for ethics consult
- Availability of decision makers and decision making capability
- Need for outside medical or mental health consultants
- Quality of life and End of Life questions and concerns
- Determination of palliative care versus cure directives
- Handling of requests for palliative and hospice care
- Percentage of service connected medical care coverage

As the analysis transitioned from stage one to stage two procedures, categories began to emerge. The typology of common indicators progressed towards groupings and subordinate indicators. The following represents several of the indicator groupings including sub-categories.

Physical/Mental Health:

Co-morbidity of mental health issues combined with physiological problems

Prognoses of physiological and mental health

Presence and course of dementia

Management and distribution of psychoactive medications

Quality of life and End of Life questions and concerns

Pain management

Comfort care

Family/Patient:

Family involvement, motives, commitment to caregiving role

Actions taken by family or patient against medical advice

Autonomy and Legality:

Importance of advance directives such as “Do Not Resuscitate” (DNR)

Patient/Veteran autonomy, decision making capability

Availability of others decision makers and decision making capability

Determining and honoring patient/veteran late life care wishes

Legal aspects such as power of attorney or guardianship

Ethics Committee Concerns/Processes:

Reasons for referral for ethics consult

Need for outside medical or mental health consultants

Determination of palliative care versus cure directives
Handling of requests for palliative and hospice care
Percentage of service connected medical care coverage

Further reflection and time spent going over the data led to the following categories of grouped concepts.

Category 1: Intra- and Interdisciplinary Interaction Concepts:

- Co-morbidity of mental health issues combined with physiological problems
- Prognoses of physiological, dementia, and mental health
- Quality of Life (QOL) and End of Life (EOL) questions and concerns
- Veteran's code status, indicating level of intervention and care provision
- Poor prognosis and futility of continued attempts to cure

Category 2: Ethics Committee Concerns & Process Concepts:

- Reasons for referral to ethics committee for consultation
- Need for outside medical or mental health consultants
- Determination of palliative care versus cure directives; when to recommend comfort measures only; requests for palliative and hospice care
- Perceptions of family members' vested interests versus patient concerns

Category 3: Family Members and Family-Institution Interaction Concepts:

- Family involvement, motives, commitment to caregiving role
- Family visits and purpose of visitation, to see veteran, or staff, or both
- Actions taken by family or patient against medical advice
- Importance of family member participation in care and care decision making
- Family member meetings and meetings with treatment teams and ethics committee

Category 4: Autonomy and Legality Concepts:

- Importance of advance directives, living wills, "Do Not Resuscitate" (DNR) directives; determining and honoring patient/veteran late life care wishes
- Patient/Veteran autonomy, decision making capability; determining capacity
- Availability of other decision makers and their decision making capacity
- Legal aspects of durable medical power of attorney, guardianship, changing code status

Feasibility study findings. The phase one feasibility study was the initial application of GTM stages one and two to a limited sample, 54 total pages, from the data set. Typically the GTM process would neither proceed so quickly to category creation, nor stop at stage two analysis. However, the impetus to determine feasibility needed to progress far enough to discover whether meaningful dimensional properties were present. The research identified initial properties of several categories including intra and interdisciplinary communication, ethics committee deliberation processes, family member involvement, and autonomy/legality concerns.

Dimensionality was apparent in properties of quality of life, prognoses, family involvement, decision making capacity, and compliance with medical recommendations. Quality of life was crucial to decisions related to cure versus care. Prognoses impacted general aggressiveness of care. Veteran and family member's assessed decision making capacity potentially shifted more responsibility into the hands of formal caregivers. And, level of compliance with medical recommendations sometimes led to more coercive forms of care when a veteran was a danger to self or others. Although there wasn't a clear sense of where higher level linkages might be found, there were indications that even this limited sample of case documentation held promise for answering the research question related to resolving ethical dilemmas, with relational ethics implications.

The emergent nature of the GTM approach required continued sensitivity to evolving insights (Charmaz, 2003; LaRossa, 2005). Findings identified initial conceptual categories and numerous dimensional properties. These findings held promise for additional insights into the phenomenon of relational ethics in caregiving. The pilot study began in March 2008.

Phase Two - Pilot Study – 2 Cases

The pilot study was conducted to confirm feasibility study findings, further test applicability of GTM to the data, and evaluate the probability of effectively addressing research questions and developing substantive theory from computerized patient record system (CPRS) case documentation. Two of the 25 cases were selected in collaboration with Dr. Kye Kim, introduced earlier, principal investigator at the VAMC for this Veterans Administration (VA) relational ethics study. Case selection and pilot study strategy were also discussed in scheduled meetings with Dr. Jay Mancini, research principal investigator at Virginia Polytechnic Institute and State University. As with the feasibility study, there was regular communication with both principal investigators to guide the research process.

The pilot study, using cases number two and nine, began on March 13, 2008. Case two (C2) represented an 88 year old combat veteran who had been a World War II prisoner of war (POW) with problematic family issues. Case nine (C9) was a 62 years old non-combat veteran with supportive family dynamics. Regrettably, both veterans were deceased when this research began.

It should be repeated regarding C2, as indicated in the feasibility study, on June 27, 2007 this researcher, as a gerontology graduate practicum student, attended an ethics committee meeting considering C2’s caregiving circumstances and visited the veteran’s bedside.

Case demographics and details. Demographics and details for the two pilot study cases are summarized in Table 10. The pilot study identified relevant psychosocial, relational, and caregiving ethics data tabs and sections within the extensive VHA CPRS archives, evaluated research-relevant timeframes, and initial findings related to study one and study two research questions.

Table 10

Pilot Study - Case 2 and 9 Details

| ITEM | CASE TWO (C2) | CASE NINE (C9) |
|---------------------------------------|---------------------|---------------------|
| Gender | Male | Male |
| Marital Status | Widowed | Married |
| Age | 88 | 62 |
| Religion | Unknown | Unknown |
| Race | White, Non-Hispanic | White, Non-Hispanic |
| Military Service | Army | Army & Navy |
| Service Era | World War II | Post Vietnam |
| Combat Veteran | Yes | No |
| Prisoner of War | Yes | No |
| Service Connected Medical Coverage | 80% | 90% |
| Ethics Committee Referral Date (ECRD) | 6/27/2007 | 1/30/2006 |
| Year Deceased | 2007 | 2006 |

Relevant data selection. One of the first methodological challenges was identifying the location of relevant data within the VHA CPRS. Case two (C2), ethics consult referral date

(ECRD) June 27, 2007, and case nine (C9), ethics consult referral date (ECRD) January 30, 2006, were explored with full access to all case related CPRS files. After two weeks of file exploratory analysis and weekly meetings with Dr. Kim to confirm that all relevant data sections were being sampled, the following two-part purposive data sampling delimiting strategy was developed. First, research-relevant data was found in specific data sections, accessed via CPRS data tabs, and not in others. Second, the issue of determining research relevant timeframes was evaluated.

Research relevant data were entries that recorded family information and involvement, formal and informal relational interactions, ethics consultations and outcomes, social and psychosocial content, and veterans' values and care preferences. Relevant timeframes were established by following the data until it stopped yielding significantly new relevant information.

Veteran CPRS case files were divided into 10 data sections and accessed via 10 separate data tabs: 1) Cover Sheet, 2) Problems, 3) Meds, 4) Orders, 5) Notes, 6) Consults, 7) Surgery, 8) Discharge Summary, 9) Labs, and 10) Reports.

Four CPRS data tabs contained data relevant to this research:

- *Notes (N)* – daily progress notes entered by nurses, social workers, doctors, etc
- *Consults (C)* – consultations on medical issues, mental health, ethics, etc
- *Discharge Summary (DS)* – case overview for each veteran discharge from VAMC
- *Reports (R)* – extensive medical information and demographics in three relevant *Reports* subcategories, *Brief Demographics*, *Clinical Reports* and *Health Summary*.

There was some overlap in data entry. Data entries were duplicated in several data tab locations including, Notes, Consults, and Reports. Others could be accessed in various combinations of Notes and Discharge Summaries, Notes and Consults, Consults and Reports, etc. The Cover Sheet data tab provided basic demographic and general veterans health information. This information was duplicated in varying depth in remaining data tab categories and more complete demographic information was stored under the Reports tab in the Health Summary subcategory. Data tabs for Problems, Meds, Orders, Surgery, and Labs emphasized the bio-medical aspects of the biopsychosocial lens (e.g., medical procedures, orders, lab results, etc.) and were not relevant to the research phenomenon of relational ethics in caregiving.

The Reports data tab held relevant subcategories, Clinical Reports and Health Summary. The Clinical Reports subcategory contained additional Discharge Summary information and

some consultation reports. The Health Summary subcategories included four additional relevant data tabs: Advance Directive Documents, Brief Demographics, Psychiatric Service, and Psychiatry. As discussed with principal investigators, this data duplication was an advantage to the research since it reduced the chances of missing meaningful data entries. Important information, especially critical incidents related to ethical dilemmas, were typically recorded in at least two locations (usually in Notes and Reports) many times in three or more (often in Notes, Consults, and Reports)

Second, certain data timeframes provided research relevant data. The Ethics Committee Referral Date (ECRD) was chosen as the pivotal date around which data collection timeframes were referenced. Since the research focused on resolution of the ethics referral dilemmas, ECRD was the most valid choice.

Third, regarding data management, by the time the pilot study was underway, decisions were made in relation to the use of *ATLAS.ti* software. The documentation for each case was converted into *rtf* format to allow for editing in case any identifying information had been missed during initial data collection. The pilot study and subsequent main study cases were converted to *rtf* format and divided into six different categories as follows:

Primary Documents for Case 2 exemplify the data structure:

| <u>Document Type</u> | <u>Primary Document</u> |
|-----------------------------|-----------------------------|
| Advance Directive Documents | P 1: Case2AdvanDir.rtf |
| Consult Documents | P 2: Case2Consults.rtf |
| Demographics Documents | P 3: Case2Demographs.rtf |
| Discharge Summary Documents | P 4: Case2DischgSumm.rtf |
| Progress Notes Documents | P 5: Case2ProgressNotes.rtf |
| Reports Documents | P 6: Case2Reports.rtf |

This data management strategy resulted in 12 primary documents for the pilot study and 150 primary documents for the total population (6 documents per case, times 25 cases).

Relevant timeframes. As explained below, the pilot cases initially suggested the following, research relevant data selection timeframes:

- *Notes (N)* – case progress notes up to six months before and after the ethics committee referral date (ECRD), to include ethics committee follow-up notes
- *Consults (C)* – relevant case consults up to five years before and one year after ECRD

- *Discharge Summary (DS)* – relevant veteran case summaries up to five years before and one year after ECRD
- *Reports (R)* – relevant case reports, including advanced directives and demographics, up to five years before and one year after ECRD

These data selection timeframes emerged from pilot study data analysis of dates containing research-relevant information. An initial sampling plan to limit file exploration timeframe from two weeks prior to the request for an ethics committee consult and ending with ethics committee recommendations was inadequate. The two pilot cases indicated significant variability in research relevant time frames referenced to ECRD. Therefore, the above timeframe guidelines were evaluated for each case in the research and modified as necessary. Most cases fit within the indicated time frames but there was significant variability. The guiding principle was to seek theoretical saturation by following case data until it stopped yielding significant new information relevant to the research. In addition the researcher followed Dr. Mancini's suggestion to collect data well beyond what appeared to be necessary to effectively conduct and complete the research process. Weekly meetings with Dr. Kim and regular communication with Dr. Mancini guided the data selection process.

Research relevant data was discovered as follows:

Case two (C2):

- 1) Data analysis limited to four categories *Notes (N)*, *Consults (C)*, *Discharge Summary (DS)*, and *Reports (R)*;
- 2) Pages of relevant data, $N=19$, $C=12$, $DS=9$, $R=16$, for a total of 56 pages;
- 3) Date ranges of two weeks for *N*, about three years nine months for *C*, eight months for *DS*, and three years eight months for *R*.

Case nine (C9):

- 1) Data analysis was limited to four categories *Notes (N)*, *Consults (C)*, *Discharge Summary (DS)*, and *Reports (R)*;
- 2) Pages of relevant data, $N=27$, $C=8$, $DS=3$, $R=12$, for a total of 50 pages;
- 3) Date ranges of almost five months for *N*, five days for *C*, one day/summary for *DS*, and three and one-half months for *R*.

For C2 *Notes* data starting two weeks prior to ECRD of June 27, 2007 was relevant to ethical concerns. *Notes* data for C9 documented a one-week stay at the VAMC, near the time of

ECRD of January 30, 2006 and prior to the veterans release to go home to die. Additional relevant data for C9 went back as far as October 12, 2005. Most case progress notes documented routine medical monitoring and procedures. Progress notes of primary research interest were those entered by the ethics team/committee members, chaplains, social workers, nursing daily care, nursing summaries, and doctors indicating ethical concerns. For C2, 19 of 176, and for C9, 13 of 119 progress notes, offered research relevant data.

For C2, 12 pages of *Consults* data, representing five separate consultations, provided research relevant information dated from June 4, 2007 to August 1, 2007. C2 had five discharge summaries between January and August of 2007, when he died. C9 had 8 pages of relevant *Consults* data during five days in January of 2006.

Nine pages of *Discharge Summary* provided research relevant data concerning veteran mental functioning, family, and legal issues. In 2006, C9 went from VAMC admission to passing away. Therefore ECRD referenced documentation time frames were generally more limited, which led to exploration of earlier data in other data sections. Significant family-VAMC interaction information for C2 was discovered in the *Reports* data section from four reports producing 16 pages of information dated from January 2, 2004 to August 8, 2007. For C9 relevant *Reports* data dated from 10/12/2005 to 1/31/2006.

The outlined date range strategy worked for the pilot study and may be feasible for the remainder of the cases but will be reevaluated as the main study progresses. *Notes (N)* data was extensive, averaging 11 to 12 progress notes per day for the two pilot cases. *Consults (C)* data provided relevant data when other perspectives or expertise were needed and were relatively rare. *Discharge Summary (DS)* data gave a good case overview and occurred on each occasion of veteran discharge from the VAMC. *Discharge Summary (DS)*, *Consults (C)*, and *Reports (R)* data provided a longitudinal view of case progression.

Pilot study data analysis. As in the phase one feasibility study, the pilot study started by opening up the data and coding what seemed meaningful; coding began with reason for the ethics consult and committee recommendations. A sampling of case documentation for those two items follows.

Record entry errors and formats were maintained, font style and size was changed to match dissertation format. The ALL CAPITAL letter entries maintained original formatting.

C2 reason for consult:

The ethical dilemma as presented by the in-patient team is as follows: Given the declining medical condition of the veteran, his poor outcome, and severely compromised quality of life, the team would like to address current treatment issues with the medical durable power of attorney on record, C2's son. There have been barriers to connecting with the son as numerous attempts have been made by various team members requesting that C2's son call VAMC to no avail. There are no known documented visits made to the veteran by any family or friends.

C2 ethics team recommendations:

The conclusion is that Dr. C will draft a letter (see Dr D's progress note this date) inviting C2's son, Medical Durable POA to attend a treatment team meeting on 7/3/07 or on 7/5/07 to review current treatment issues. C2's son was also offered transportation in the event that that is a barrier to him visiting. Dr. D will send this letter out via regular postal service as well as send a copy certified returned receipt in hopes the team will get a response from C2's son. Based on this outcome the Ethics referral team agrees to attend the family treatment team meeting and/or plan to reassemble on 7/5/07 @ 11:00a to review progress of case.

There was no further documentation on the plan to reassemble on 7/5/07. Coding for these entries included, poor prognosis, quality of life, power of attorney, barriers to communication, no family visits, transportation offer, certified letter communication, and family treatment team meeting.

C9 Reason for consult:

62 yo WM WITH H/O DM, SPINAL STENOSIS, ESRD ON HD, GAMMOPATHY AND SERUM ALBUMIN <1 ADMITTED TO ECRC ON 1/25/06 FOR REHABILITATION AND CARE WHILE ON HEMODIALYSIS. LONG DISCUSSIONS WITH FAMILY AND WITH PATIENT CONCERNING CARE ISSUES. PATIENT REQUESTED DNR STATUS AND HAS BEEN REQUESTING DC TO HOME SINCE LAST FRIDAY. FURTHER, HE REQUESTS THE DIALYSIS BE STOPPED. HE UNDERSTANDS THAT HE WILL DIE WITHOUT THE DIALYSIS BUT IS ADAMANT THAT HE WANTS TO GO HOME TO DIE.

APPARENTLY, THESE ISSUES WERE RAISED SEVERAL TIMES WHILE HE WAS AN INPATIENT AT LOCAL HOSPITAL AND THE WIFE AND THE PATIENTS DAUGHTER NOTE THAT HE " JUST ISNT GETTING BETTER" AND THEY FULLY SUPORT HIS DECISION.

C9 ethics team recommendations:

Patient is not thriving on dialysis. Patient appears competent to make decisions as reported by Dr. H. Patient requests to stop dialysis with the knowledge that he will die. Patient's family supports his decision to stop dialysis. Patient also requests that he be discharged and go home to die. A progress note between Dr. Hxxx and Dr. Kxxx supports patient's decision to stop dialysis which is of no real benefit to patient (by Dr. Kxxx). Dr. Kxxx stated that this will allow the patient to remove any barriers for patient to go home. The Ethics committee members all agreed that patient's actions and support of staff is appropriate.

Coding and code categories for C2 and C9 ethics consults. Coding for these entries included, ECRC (Extended Care and Rehabilitation Center, located at the VAMC) admission, DNR (Do Not Resuscitate, advanced directive to not take aggressive measures near end of life, allow veteran to die), family involvement, discussion with veteran, discussion with family, DC (Discharge) home, home to die, family agreement with veteran, decision-making capacity, stop treatment, and all in agreement.

By this point, coding using *ATLAS.ti* software, had produced 12 code categories. Samples of codes and categorical groupings follow.

Under the category of Advanced Directives (AD):

| | |
|-------------------------|----------------------------|
| AD:DISC W/VET OR AGENT? | AD:DNR:DOC:STAFF PHYSICIAN |
| AD:DNR | AD:DNR:GEROPSYCH |
| AD:DNR RESCINDED | AD:DNR:MPOA:POA? |
| AD:DNR:CARE WITHHELD | AD:EDUC/INFO PROVIDED |
| AD:DNR:DETAILS | AD:FULL CODE |
| AD:DNR:DOC:RESIDENT | AD:GUARDIAN DESIGNATED |

Under the category of caregiving (CARE):

| | |
|----------------------|--------------------------|
| CARE:ADL'S & IADL'S | CARE:ECRC:EXTENDED CARE? |
| CARE:ASSISTED LIVING | CARE:FAMILY |

CARE:COMFORT CARE ONLY

CARE:ECRC SCREEN

CARE:LEVEL CHANGE

CARE:LEVEL OF CARE

CARE:NURSING HOME

CARE:PLACEMENT

CARE:FOLLOW UP CARE

CARE:GOALS

CARE:PLACEMENT HOME

CARE:RECOMMENDATIONS

CARE:RESTRAINT & SECLUSION

A specific example that raised ethical questions, of how documents were analyzed as part of code category development, in this case LIFESTYLE, under a specific code (QOL), or quality of life, follows. LIFESTYLE:QOL was a significant issue for C2 as indicated by the code-linked quotations.

P 5: Case2ProgressNotes.rtf - 5:67 (5:67 indicates primary document 5, line 67)

Codes: [LIFESTYLE:QOL]

Documented Quote: 88 yo demented, bedbound, total care pt. Has a PEG and J tube, does not eat by mouth. Has a permanent trach. Does not communicate. Spends the majority of his life on icu or acute medicine, briefly stays in ecrc between these admissions, but is sent back to acute as soon as he decompensates.

P 5: Case2ProgressNotes.rtf - 5:69

Codes: [EOL:HOSPICE/PALL CARE] [LIFESTYLE:QOL], note that documented quotes could be cross, or duplicate, coded under several different code categories, in this quote end of life palliative care was also coded.

Documented Quote: Dr. Lxxx and I consider this pt's care to be futile and his quality of life poor. We suggest palliative care at ECRC. If the son cannot be reached, can these proceedings take place? If the son is reached, and still wants everything done, are we obliged to continue even though most physicians would consider his care futile and in my opinion, inhumane given his quality of life?

P 5: Case2ProgressNotes.rtf - 5:178

Codes: [LIFESTYLE:QOL]

Documented Quote: C2 is completely bedbound. He is completely non verbal. He cannot communicate by gestures or any other means. He is trach dependent. C2 cannot eat and is completely dependent on tube feeds. He is demented and total care. He spends the

majority of his life on acute medicine or in the icu (*intensive care unit*). His condition will never improve. The son, in the past, demands full code. I would like to speak with him regarding this but cannot reach him. I think aggressive treatment is futile and discussed this with Dr. Lxxx today from the icu who agrees.

P 5: Case2ProgressNotes.rtf - 5:180

Codes: [LIFESTYLE:QOL]

Documented Quote: Aggressive care appears futile and does not seem to be in the veteran's best interest given his quality of life at this stage of his illness.

Here is a sample quote for case 9 under the LIFESTYLE:QOL code that was also coded under an admission evaluation code.

P47: Case9ProgNotes.rtf - 47:45

Codes: [ADMISSION: EVAL] [LIFESTYLE:QOL]

Documented Quote: 62 Y/O white male with multiple medical co-morbidities has been steadily decompensating over the last few months, in chronic renal failure on HD since October and has had multiple line infections and bacteremia, currently empirically treated for endocarditis. Pt has no prior psychiatric hx, is now apathetic, anhedonic and withdrawn, thinks there is no reason to live, has had suicidal ideation over the past weeks but no intent or plan. Feels hopeless and helpless, says he will continue to get worse, he can't hunt or fish, can't perform his ADLs and is frustrated about his overall deteriorating condition. Began experiencing these feelings around the time of hospitalization. Reports excessive sleepiness, (pt on oxycodone, lorazepam and temazepam), recent change in appetite and intake partially due to his increasing requirement for assistance with feedings, admits energy loss, decreased concentration and compromised comprehension skills, admits psychomotor retardation. Denies audio, visual and tactile hallucination, denies delusions. Admits transient SI in the past with no intent or plan. Denies HI. Patient noted to have waxing/waning cognition on serial exam and the medical resident noted that the patient appears to be having absence-like spells. He has a hx of seizures. Dilantin level 7.

For additional information on *ATLAS.ti* codes and code families see Appendices.

Case two findings. Pilot study of C2 documentation provided insight to how ethics committee members, who are also VAMC active staff members, perceive and evaluate ethical dilemmas and make recommendations. It also raised questions regarding clarity of communication within the VAMC as well as communication between VAMC staff and veteran family members related to nature and level of care provided.

Notes data for C2 indicated that as of the ECRD of June 27, 2007 this veteran was described as an 88 year old white male, demented, bed bound, total care patient. He was a World War II combat veteran who had spent time as a prisoner of war. The reason for requested ethics committee consult was that family-requested aggressive medical treatment was described by attending physicians as, “futile and his (veteran) quality of life poor.” One doctor continued, asking about provision of aggressive care, “are we obliged to continue even though most physicians would consider his case futile, and in my opinion inhumane, given his quality of life?” The dilemma was exacerbated by the inability to engage the patient’s son, who identified himself to VAMC staff as the only available family decision maker, regarding quality of life and level of care concerns.

The ethics committee met and made recommendations on the ECRD. *Notes (N)* data on 6/27/07 indicated that “There were no known documented visits made to the veteran by any family or friends.” After consultation with the Veteran’s Administration (VA) attorney the attending disciplines (three registered nurses, a geriatric psychiatrist, chaplain, attending doctor, social worker, and gerontology graduate student) met. Recommendation was made that the attending doctor send a letter by both regular and registered mail explaining the necessity for the veteran’s son, the Medical Durable Power of Attorney, to attend a treatment team meeting on 7/3/07 or 7/5/07, or otherwise become actively engaged as an advocate given his father’s advanced dementia, physical health, and general quality of life.

Relational ethics implications of C2 caregiving documentation. Several ethical caregiving observations emerged from analysis of C2 documentation. First, interdisciplinary team patient treatment plan *Notes* data on 6/19/07 indicated that, “the following treatment team members collaborated in the development of the patient treatment plan: Resident, Nursing, Veteran.” The veteran was diagnosed with “advanced dementia,” requiring “total care,” with a “bed bound prognosis,” as early as 2/23/07. In other words he had not been able to effectively communicate

for at least four months prior to this entry. Also, as documented, neither family nor friends had visited the veteran in over five years.

Careful reading of *Consults* and *Reports* data indicated that the patient actually had two sons. This was not made clear in CPRS documentation until 8/1/07 when one son, first initial R, stated that, “he and his brother are going to come visit their father either Friday or Saturday of this week to make a decision about his care.” Another data entry on 8/1/07 states, “Patient’s POA (Power of Attorney) is son R, who has not seen patient in five years, is very difficult to get ahold of, and insists that patient remains *full code*.” Note that *full code* means all medical means available, including intrusive and heroic measures, will be taken to keep the veteran alive. The entry continues, stating “Patient does have a second son, who has not seen father in 10 years but states he has always respected his father. Wife of son has been encouraging him to come see father and wife is easily reachable.” The lack of clarity in the documentation concerning the existence of two sons, with perhaps very different accessibility and views on their father’s care, has significant ethical implications.

As early as 2004 there were conflicting directives regarding veteran’s care with unclear references to which son may have been communicating with VAMC. According to 1/2/2004 documentation, a *Do Not Resuscitate* – DNR directive was made by one of the sons, name not indicated. A DNR directive is the exact opposite of full code described above i.e., no heroic measures or intrusive medical interventions would be made to prolong life. The 1/2/04 progress notes reads:

I spoke with vet’s son regarding end of life issues as well as resuscitative measures that may have been discussed in the past. He attempted to speak with father sometime ago about these decisions but his dad was reluctant to do so. He states that his mother died 10 years (*ago?*) and very ill for 18 years and suffered tremendously. He states that he does not believe that his dad would want heroic measures should he suffer cardiopulmonary arrest. He is the current POA and has been handling all of his affairs for sometime. He is the only family member available to make decisions. Will honor this wish and write for DNR orders (CPRS Progress Note, 2004).

The demographic notes on this veteran indicated that C2 was never married while the above report mentions both father and mother, although the pronoun reference of “his” is unclear. It may be that the veteran never married their son’s mother or, the son may have been

talking about the veteran's mother i.e., the son's grandmother. It is also possible that this personal information was assumed or mistaken. By all indications VAMC staff communication with the same son later that year, although the son's name is not indicated in the progress note, rescinded the DNR order. The 11/29/04 progress note and addendum reads:

In lieu of recent events, the vet's son has stated that he wishes for everything to be done for this vet should he become acutely ill. He is now listed as full code. During the recent conversation, his son clearly expressed his wish that everything should be done for his father. He was fully informed of his father's mental/ medical status and prognosis (CPRS Progress Note, 2004).

It is reasonable to assume this was the same son who held the Durable Medical Power of Attorney. However, awareness and documentation of the existence of the second son may have offered another, ironically perhaps more accessible, view on the veteran's caregiving wishes. From the *Consult* data entry on 8/1/07 it appeared that the second brother was not involved or directly consulted until the veteran's health crisis required discharge from the VAMC to a chronic ventilation facility. Although not entirely clear from the data, one son, who held the power of attorney (POA), had not seen his father in person for five years, while the other brother had not visited his dad for 10 years. There was no documentation on possible communication between the two brothers.

Another relevant entry was made in the *Reports* section by a social worker on 5/6/2005 as follows:

Vet is too demented to make decisions or make Adv. Dir. He had not made these decisions earlier in his life. I have discussed the vet's wishes with his son, R, and son does not know what his father would have wanted and he is fearful of making a wrong decision (CPRS Progress Note, 2005).

This entry conflicted with the DNR that existed for almost 11 months in 2004. The primary reason for ethics committee consultation in this case was directly related to caregiving code status i.e. aggressiveness of care. Once the veteran's code status was changed from *full code* to an updated *Do Not Resuscitate* he passed away not long after.

Case nine findings. Pilot study of C9 documentation provided insight into how ethics committee members, as active VAMC staff members, resolved ethical dilemmas and made recommendations when family and veteran's wishes were coherent and congruent. An ethics

committee consult was requested due to C9 veteran's request to return home to die rather than continue curative care.

C9 documented numerous and timely interdisciplinary *Notes* and *Consults* between and among VAMC staff, veteran, and family members leading to consensus. These consults, evaluations, and deliberations were completed within a five day period and the veteran was released to go home to die. Post discharge documentation of medical pain management and case monitoring indicated an effective transition from curative medical intervention to comfort palliative care. This case provided an example of how well processes at both the internal VA interactions and formal-informal caregiver interactions level can work.

Notes data for C9 indicated that as of the ECRD of January 30, 2006 this veteran was described as a 62 year old white male with numerous medical problems, had been on dialysis for several months, and was living in constant pain. A primary care doctor's progress note from 10/12/2005 indicated that in spite of many medical problems, "no depression reported." October of 2005 began a transition from primary medical care in the private sector to care at the VAMC. The veteran had suffered a seizure in December of 2005 due to an overdose of prescribed pain medication. He was admitted to VAMC on 1/25/2006 for rehabilitation and dialysis and had significant pain due to problems with his feet and back as well as a prognosis, "that he probably has 6 months or less to life in light of multi-organ disease."

Veteran C9 had full emotional and relational support from his wife and daughter. A psychiatric progress note on 1/26/2006 indicated that, "Patient has no prior psychiatric history, is now apathetic, anhedonic and withdrawn, thinks there is no reason to live, has had suicidal ideation over the past weeks but no intent or plan." A psychiatric consult follow-up note the next day, 1/27/2006, noted, "Patient admits fleeting thoughts losing motivation to live, primarily due to episodes of poorly controlled pain, but says he wants to live, and no intent or plan to hurt himself."

Notes data for C9 entered by a staff physician on 1/27/2006 established a DNR – Do Not Resuscitate advanced directive. The entry stated, "I spoke with the patient and his wife today and he requested DNR status..." By 1/29/2006 a nurse's note stated that, "Vet advises that he is tired and uncomfortable. He does not want anything other than comfort care." *Notes* data continued, reporting that the veteran said, "Can't you just provide me with more medicine just to keep me comfortable, nothing more?" The nurse documented the continued interaction, "I spoke to him

there is a care termed 'palliative care' which provides patient with comfort measures only patient says he is interested in this type of care. Patient asked me if he could talk to the weekend doctor about this type of care getting started."

This exchange between the attending nurse and the veteran patient documented an example of relational ethics at work. The care giver took the time to listen and respond while the care recipient was able to express desired level of care. Within two days of this interaction the veteran's wish, supported by his family, was granted; the veteran was discharged to hospice care and had five pain-managed weeks at home with his family before dying.

Relational ethics implications of ethics committee consult for C9. The veteran's wish to go home to die was expressed on 1/30/2006 and led to the interdisciplinary ethics committee consult. The disciplines participating were the two nurses, chaplain, and two physicians. A social worker progress note that morning stated, "Veteran has been on dialysis for several months. He is in constant pain. He has elected to stop dialysis and return home." The social worker also recorded, "Veteran has an extremely supportive wife and daughter..." and "Veteran's son lives out-of-state and plans on returning home this week to spent time with veteran."

The ethics referral note of 1/30/2006 reported, "He requests the dialysis be stopped. He understands that he will die without the dialysis but is adamant that he wants to go home to die." The staff physician requesting the ethics consult also wrote, "The wife and patient's daughter note that he 'just isn't getting better' and they fully support his decision." The ethics committee note supported the veteran's request as follows, "The Ethics committee members all agreed that patient's actions and support of staff is appropriate." Further, an Ethics Team Follow-Up note on the same day, 1/30/2006, documented a mental capacity evaluation as part of comprehensive evaluations prior to discharge home.

He was seen by this underwriter today. C9 was very alert and cooperative.

He was socially appropriate and expressed his appreciation of this underwriter's visit. He clearly articulated his wish to return home as soon as possible and to discontinue the dialysis. He was willing to accept any other measures that would keep him comfortable such as a hospice care. He had no delusions or hallucinations. His affect was with some sadness but grossly appropriate for the content of the conversation. His mood was described as "fine." He has no active suicidal ideations. He clearly expressed his understanding of the outcomes of his decisions. His rationale to return home without

active treatment: He stated, "I'm just tired," "I know where I am going and I am ready." "I am not scared," "My family agrees that I should be home," "I'm not getting better."

Assessment: He is determined to have a capacity to make an informed decision(s). There was a question about him possibly having depression or delirium. However, his depressed affect appears to be more related to the existential decisions that he has made for his future. He might have underlying intermittent delirium associated with polypharmacy and ongoing medical conditions. During this interview, he had no fluctuation of consciousness at all. Even if he has underlying depression or delirium, either condition is not qualitatively or quantitatively severe enough to affect his judgment (CPRS Progress Note, 2006).

This thorough mental capacity evaluation offered another documented example of effective relational ethics. The evaluator took note of the context of signs of depression and the opinions of attending physicians and members of the ethics committee while validating the veteran's existential situation and wish to return home to die. Given the contents of earlier *Consults* data presented below the above evaluation was particularly important in supporting veteran and family wishes to terminate VAMC care.

Consults data on 1/26/2006 documented concurrence with a psychiatric evaluation of "Depressed mood in patient with multiple medical co morbidities;" attempts to use psychoactive medications to help with depressive symptoms also presented complications. *Consults* data reported, "Dialysis has been known to induce mood and personality changes. A trial of an SSRI can be started empirically but note that antidepressants used under these clinical scenarios often are less effective." Another psychiatric consult on 1/27/2006 noted the following:

Patient reports that he would not commit suicide because of strong religious beliefs, no prior history of suicide, no family history of suicide, no direct access to weapons.

Describes nocturnal disorientation that occurs after waking up in the middle of the night, says these episodes might last for hours. Patient complains about staff interaction and not getting the assistance he often needs. Denies audio, visual and tactile hallucinations, denies homicidal ideation. Staff and spouse note episodes of confusion and fluctuating level of alertness today (CPRS Consult, 2006).

Thereby the veteran was evaluated by several mental health professionals regarding his mental capacity. Observations by both VAMC staff and the veteran's wife were acknowledged

and validated. The outcome was a discharge on 1/31/2006 to “go home to die’ documented in the *Reports* data, along with referral to hospice services. An entry relevant to relational ethics between husband and wife was observed and entered on the same date by a chaplain as follows:

C9 was asleep when I stopped by this morning. I spent some time talking with his wife, who was appropriately tearful about his prognosis, and ready to take him home this afternoon. I provided spiritual and emotional support, gave her my office phone number, and invited her to call me at any time (CPRS Report, 2006).

Relevant *Reports* data entered by the veteran’s primary physician on 1/31/2006:

Significant Medical History (pre-existing and/or arising during hospitalization) no changes, patient and family decided to stop dialysis and all care except comfort measures, patient wants to go home to die with hospice care. Patient not doing well at all, sleeps most of the time, has not been eating for 2 weeks and wants to leave the hospital and go home for the rest of his time. There was an ethics meeting and all agree that it would be o.k. for him to go home for the time left (CPRS Report, 2006).

This researcher noted in the wording of this *Reports* data entry an implication of ‘permission granted’ for the veteran to return home to die. The tone of the documentation did not convey a sense of collaboration and respect for the veteran’s decision honoring this care recipient’s autonomy. Rather, the medical professionals evaluated the reasonableness of his request in light of their medical prognosis to reach a consensus and willingness to allow veteran’s discharge to home and hospice care. There was an underlying sense of maintaining a position of professional agency even in letting him go. Of course this ongoing medical involvement benefited the veteran by providing ongoing medications for essential pain management.

The above formal and formal-informal caregiver interactions processes and interactions led to a discharge from the VAMC on 1/31/2006 which resulted in the following *Discharge Summary* data subsequently entered in the CPRS on 3/2/2006.

The case was discussed at length with the patient, and the patient elected to initiate a DNR status. The case was discussed with the patient on January 30, 2006, and the patient is desirous of discontinuing hemodialysis. The patient fully understood the risks of stopping this, which potentially could be death. The patient discussed with me at length that he wants to be discharged to home as he is simply tired of dealing with all of

the medical problems since initiating dialysis. Please see my note dated January 30, 2006. Following this, an Ethics consultation was obtained, and the patient was seen and was felt to be cognitively intact per Dr. K, and further, the Ethics Team felt that this was a reasonable decision based on the patient's history of failure to thrive. Subsequent to this, the patient was discharged to home with hospice care and will be followed by Hospice in _ County (CPRS Discharge Summary, 2006).

This case represented successful and appropriate transition from VAMC care to home and hospice comfort care per veteran care recipient and family wishes. It gave significant insight into the formal and formal-informal caregiver interactions processes that supported that transition. Perceptions, descriptions, and evaluations of ethical dilemmas were well documented. The process of resolving ethical dilemmas was also documented along with the impact of conversations and written interactions on recommendations and outcomes.

Pilot study findings. The pilot study:

1. Identified and confirmed location of ethics and relational ethics data within CPRS relevant to this research
2. Evaluated timeframe guidelines for relevant data categories
3. Recognized the need to seek data beyond the timeframe guidelines when more extensive and relevant case information was available
4. Confirmed relevance of LaRossa's (2005) first two principles; language central in social life of medical care at the VAMC, and word indicators confirming initial concepts and categories.
5. Continued and confirmed initial coding and concept creation as valid starting point for main study per Daly's (2007) first two stages.
6. Found CPRS data that documented perceptions, descriptions, and evaluations of ethical dilemmas
7. Discovered data that described internal VA interactions VAMC and ethics committee processes seeking ethical dilemma resolution
8. Identified formal-informal caregiver interactions issues and insights in communication between VAMC staff veteran's family members
9. Explored documentation that described the process of interpersonal interactions both internal to the VAMC and between formal and informal

caregivers related to ethical resolution efforts, recommendations, and outcomes.

10. Established data management strategy using *ATLAS.ti* software.

Phase Three – Main Study – 25 Cases

As explained, the *Phase Three Main Study* consisted of two separate studies of relational ethics in veterans' caregiving. Study one focused on formal relations internal to the VAMC including documented communication between formal caregivers and between formal caregivers and veteran patients. Study two focused on formal-informal interactions i.e., between the formal caregivers of the VAMC and veterans' informal caregivers, i.e. family, friends, and significant others. The two studies explored different aspects of the data and produced different results. Studies one and two used the same data set of 25 cases, analyzed from the two perspectives described.

Primary document descriptions and summary. The researcher used *ATLAS.ti* qualitative software to facilitate data management, organization, and analysis. The data were divided into six primary documents for each of the 25 cases. This resulted in 150 primary documents for the 25-veteran population. The six content areas were Advance Directives, Consults, Demographics, Discharge Summaries, Progress Notes, and Reports.

In order to limit document size and facilitate data analysis, advance directives and demographics were handled as separate case documents. They were originally part of the Reports data tab section of the Computerized Patient Record System (CPRS). The six content areas included the following types of data:

Advance Directives - included dnr (do not resuscitate) orders, full code (aggressive medical intervention order to do everything possible to save a veteran in distress), POA (Power of Attorney), DPOA (Durable POA), and Medical POA information. There were 108 advance directives in the complete data set.

Consults - included requests for and actual consultations for the 25 ethical dilemma cases. Outside expertise was seldom called into the VAMC, most of the consult requests were for the expertise of staff internal to the VAMC in this research. There were 178 separate consults in the complete data set.

Demographics - provided demographic data as presented in Table 8, including percentage of service connected care which indicated the amount of care cost was covered by the VA. There was one page of demographic information for each of the 25 cases.

Discharge summaries provide a more longitudinal look at veterans' cases. I chose a 5-year pre- and post-ECRD timeframe since the data provides the longer view not normally available in many cross-sectional studies. Discharge summary data was ultimately deemphasized in this study in order to maintain focus on data entries in closer proximity to the ECRD which had more impact on ethical dilemma resolution. There were 125 discharge summary documents in the complete data set.

Progress Notes provided the most extensive view of the case and veteran from numerous professional perspectives. Progress notes for all cases were reviewed extensively and approximately 10 pages of data were reviewed for every page chosen and included in the data set. Between 14,000 and 15,000 pages of data were reviewed and 1,439 pages were included in the data. There were 783 separate progress notes in the complete data set.

Reports provided more extensive professional assessments, prognoses, etc. They were sometimes part of a consult request. The most extensive reports were related to psychiatry, psychology, and mental health assessments and issues. There were very few reports that were not recorded in progress notes documents as well. There were 378 report documents in the complete data set.

In summary, advance directives data connected specifically to clarifying agency and agenda; consults provided mostly biological data with some indications of professional caregiver role salience; demographics gave brief personal information and service related medical coverage percentages; discharge summaries presented a longitudinal overview of the case each time a veteran was released from the VAMC; progress notes yielded the most insight into relational ethics in action and included all ethics committee interactions; and reports, most often duplicated in progress notes, provided details primarily related to psychiatric and clinical psychologist's assessments.

Details of GTM stages and procedures (see Table 6) from opening coding, through creating categories and linking, to telling the theoretical story will be presented in detail in chapter four for study one and chapter five for study two. Chapter six will discuss findings and

conclusions for the entire study including the resultant substantive theory for relational ethics in caregiving for veterans.

Ethics committee consults and recommendations. Ethics consults and VAMC ethics committee involvement identified the research population and provided the core focus of the research. Reasons for requests for consults and committee recommendations for each case are presented in Table 11.

Table 11

Ethics Consults – Reason for Consult Requests and Committee Recommendations

| Case # | Reason for Request | Recommendations |
|--------|--|---|
| 2 | Declining medical condition of the veteran, his poor outcome, severely compromised quality of life, the team would like to address current treatment issues with the medical durable power of attorney on record, C2's son. There have been barriers to connecting with the son; no known documented visits made to the veteran by any family or friends. | Draft letter inviting C2's son, Medical Durable POA, to attend a treatment team meeting to review current treatment issues. C2's son also offered transportation if barrier to him visiting. Send letter via regular postal service and via certified return receipt. Based on response the Ethics referral team to attend family treatment team meeting. |
| 3 | Veteran is a 100% Service Connected (SC), 81 years old with MS, Apiration PNA, and collapsed lung with very poor prognosis. The attending MD requested that veteran's son come in to meet with the TEAM to discuss veteran's code status and he continues to refuse and insist that veteran remain a full code even given veteran's compromised medical condition. | EC members do not feel that the issue is an ethical dilemma but issue of clarifying legal NOK willing to make decisions on the veteran's behalf since unable to do so for himself. NOK to be clarified regarding whether veteran's wife, his son, on record or any other children are alive and who among them is legally responsible to make medical decisions for the veteran. Provide education to the legal NOK on responsibilities and expectations for participating in the treatment plan for veteran. |
| 4 | 53 year old veteran with decision making capacity, but severe medical illnesses and disabilities, wants more autonomy, often requests AMA discharge; staff and family feel he cannot take care of himself. Staff | EC recommends: 1) Neuropsych testing, 2) step-wise progression to independent living, 3) contact VA district counsel for guidance regarding patient desire for discharge when questions arise regarding |

Table 11 (Continued)

needs help deciding what to do. Can we discharge this patient independently if he wants to leave? If we cannot discharge patient can we require him to sleep in a room without access to water to prevent him drinking too much?

veteran's decision making capacity.

5 Veteran's discharge back to Adult home stopped secondary to pulmonary issues. During admission determined that veteran required continuous oxygen, precluding return to X Retirement home. Difficult decision made by DPOA - his mother and his sister - to only have oxygen at night so vet could continue to smoke. Pulmonary not receptive to providing a portion of oxygen treatment that vet requires on these terms.

Patient's/family autonomy shall be upheld, that he be allowed to return to X Retirement Home with the stipulation that should his condition worsen, he will return to VAMC for further treatment and alternative residential arrangements be made.

6 Veteran contacted VA National Ethics Referral line to request a review of his case, and stated that he was "denied treatment and medication" since he did not report to the lab for urine screen. Veteran does not understand why he is being refused treatment and thinks it unfair for him and other veterans.

EC reviewed veteran's medical clinical record and Contract For Narcotic (Opiate) Prescription protocol which veteran and attending physician, Dr. Hxxx, signed on 4/15/05. EC finds no basis for an ethical dilemma at this time. Veteran to be notified in writing of this decision.

7 75-year-old male veteran initially admitted to VAMC for left MCA stroke on 4/1/06. A PEG was performed on 4/25/2006 due to dysphagia. He was subsequently transferred

1) Locate scanned advance directives in CPRS, but no documentation about his wishes. It was all crossed out; no way to know his wishes through medical records.

Table 11 (Continued)

| | | |
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| 7 | to ECRC for further care and disposition. Per the 2-2 nurses and Dr. B, he pulled his PEG tube out despite the sturdy wrappings. At this point, his wife and daughter do not wish the tube re-inserted. Review ethical issues involved in the decision-making process. | 2) Based on his chart review and examination, clear that he had no capacity to make informed decision(s) as to his welfare including health care. He didn't know he had a feeding tube. 3) He appeared comfortable, alert, denied experiencing any pain, no indication of emotional strain associated with PEG tube. 4) Since veteran has no capacity, reasonable for treating team to seek advice from NOK, his wife. As long as his NOK wishes the PEG tube not re-inserted this time and the patient's attending physician doesn't have a conflicting opinion, Ethics team doesn't see any possible ethical issues. |
| 8 | Discussion of Code Status with the patient's wife for 73 year old veteran, who appears to have end stage dementia, is unresponsive to verbal stimuli, being fed via PEG. Multiple readmissions. Question of quality of life and maintaining full code status. | Contacted veteran's wife. She cannot come in during the week until school is out and states I'm "not going to sign those papers anyway." She knew meeting was to discuss not providing vet with all care he might need. She would "not do anything to prevent him from a day of life." Wife thought veteran was functional and responded to family and until he became brain dead she did not want to change the course of treatment. MD informed. |
| 9 | Patient requested DNR status and requesting discharge home, that dialysis be stopped. | Patient is not thriving on dialysis; appears competent to make decisions. A progress |

Table 11 (Continued)

Understands that he will die without dialysis; adamant that he wants to go home to die. Veteran's wife and daughter fully support his decision.

note between Dr. Hxxx and Dr. Kxxx supports patient's decision to stop dialysis which is of no real benefit to patient. The committee members all agree with patient's actions; support of VA staff is appropriate.

10 To address ethical issues of continued care for veteran patient who is chronically a danger to others and in need of treatment for sadism and pedophilia. Veteran is ineligible for treatment programs targeting these behaviors; they only exist in prisons. Veteran has never been charged, has not, and most likely will not, surrender him self to the legal system to access care. Confinement of patient here, where he is unable to receive the treatment he needs is clearly a risk factor for exacerbating his depression. However, he represents a serious risk to the community as his pedophilic urges are unrelenting.

1. Confer with hospital administration to discuss further interventions to provide appropriate treatment for patient.
 2. Patient should not be discharged as he is considered a danger to himself and others.
 3. VAMC Police to make more visits to patient's ward, offer refresher course to staff on managing aggressive behavior.
 4. Staff should be offered support therapy
 5. Continue looking for a facility that could provide the therapy the patient needs.
 6. Attempt to locate an expert in the treatment of such behaviors and consider having them come here as a consultant.
-

11 Staff physician requested ethics consult to discuss C11's case due to request from Mr. and Mrs. C11 for Hospice care. Requested assistance deciding how Mr. C11's needs could be addressed; and help, if appropriate, to do this referral.

After reviewing appropriateness of hospice care per American Hospice Association with Dr. Hxxx, doctor and EC agreed that hospice services should be initiated with SW visit to evaluate caregiver, patient and home situation to see if additional assistance is needed. Patient and his wife may elect inpatient palliative care due to Service Connected (SC) disability status or

| <u>Table 11 (Continued)</u> | they can explore non-institutional hospice; may choose nursing home (NH) placement with hospice support. Review spiritual needs and ask the family if they need intervention of their minister. |
|--|---|
| <p>12 Family wanting to withdraw care, possibly this weekend. Veteran intubated and sedated for two weeks. Next step is trach tube placement which family doesn't want. Veteran has advanced directive; current clinical condition unlikely to improve.</p> | <p>Living Will completed in 1995 and per nursing staff, he further has discussed wishes with his sister. EC recommends sister be educated about options after the surgical and medical teams collaborate regarding his case.</p> |
| <p>13 Nurse requested consult due to veteran request to stop dialysis. Nurse asked patient if he wanted PEG tube, patient said, "no, but my wife does". Three days later patient said, "help", when ask what was wrong he stated, "I'm so tired". Asked patient if he was tired of dialysis, and he answered, "yes", I explained that without dialysis he would die. I said "do you understand?" patient responded, "yes". Notified MD and nurse manager. Same day patient told another nurse "I have to come off now, I can't take anymore." Called for EC consult.</p> | <p>1) Conflicting observations on mental status per dialysis staff, can be mentally clear although often tired. Wife reports he is often "in and out." Need to establish mental capacity; may have underlying cognitive dysfunction or delirium due to complicated medical conditions. Recommend consult to Psychiatry for evaluation.</p> <p>2) Question about possible undertreated depression; has been on citalopram but no documentation about Tx response. Wife states his mood has been always the same. Optimize control of his depression, if possible, for veteran's benefit.</p> <p>3) His wife claims that he has hearing difficulty; needs to be clarified.</p> <p>4) Clinical team should work with his</p> |

Table 11 (Continued)

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| | <p>family (wife and two sons). Make sure his spiritual needs are met; wife reports little interaction with his priest. Should provide an assistive device to improve veteran's communication with his priest (for instance, pocket talker).</p> <p>5) Follow up meeting with EC if needed.</p> |
| <p>14 Patient is in Intensive Care Unit (ICU) on ventilator. Family is leaning toward taking him off the vent yet aggressive treatment and new work-up is ordered as of today. Patient had been Do Not Resuscitate (DNR). Question is asked why are we doing extensive work up at this point if patient is a DNR and Family has requested terminal extubation (removal of feeding, etc. tubes)?</p> | <p>1. Suggest Social Work Services (SWS) get involved in case, conduct a search for family member, clergy, neighbor or someone who has experience communicating with family and can serve as a support or advocate for the family.</p> <p>2. Discuss case with EC this week to review procedure and documentation of DNR orders, Advance Directives, Living Wills, and how to address changes in postings in CPRS when code status changes.</p> |
| <p>15 76 year old veteran with severe anoxic brain injury. Patient seen by neurology and ICU team; they mutually agreed that patient has no chances of meaningful recovery. He has a Living Will in chart, stating if attending physician deemed him being terminally ill he would not want any aggressive treatment. Disagreement in family as to whether they accept diagnosis and poor prognosis given by treating team (girlfriend leans toward <u>Table</u></p> | <p>EC noted a later entry/resolution, ethics consult no longer needed, girlfriend is medical power of attorney, she is in close touch with son, sons in agreement with her honoring veteran's dnr/comfort care wishes. Review case with attending physician, Dr. Mxxx.</p> |

Table 11 (Continued)

withdrawing care - she is POA, patient's sons seem to have doubts).

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| 16 | Staff physician's judgment differs from psychiatry and neuropsychiatry in terms of veterans decision making capacity and forcing him with Temporary Detention Order (TDO) ; request re-evaluation for competency. Physician feels that VAMC might be interfering with veteran's autonomy and personal wishes; feels that patient is competent in decision making as he has good basic understanding of his illness, plans, management; additionally he is not delirious, there are no significant judgmental disturbances; also told me how he manages at home with logic and explanation: hence ethics consult requested for third opinion. | C16 been seen by psychiatry and neuropsychiatry. They suggested assistive living arrangements and TDO if he attempts to leave AMA. Veteran refuses to go to assistive living, determined to go back to his home. He told staff there is someone who comes in from time to time and assists him. He packed his belongings and is ready to leave. Dr.Axxx feels he should be allowed to return home. Dr. Sxxx consulted and final decision is to allow him to return home if he will consent to home health services. He has consented and arrangements are being made by social services. |
|----|--|--|

| | | |
|----|---|--|
| 17 | Patient on vent for multiple days, liver failure, makes no purposeful movements, family showing many concerns about veteran's prognosis. Family well aware patient's present condition and of patient's feelings of living in this condition. Request advice on continuing care status. | EC member, Social Worker, spoke with Registered Nurse (RN) in Intensive Care Unit (ICU). RN stated that referral was cancelled. Clinical team have met, further discussed case and have resolved ethical issues. |
|----|---|--|

| | | |
|----|---|--|
| 18 | End of life decisions by family pending. Patient recently trached, now attempting | Arrange for EC meeting/conference call with patient's two brothers; unfortunately, |
|----|---|--|

Table 11 (Continued)

wean from vent. Patient only responsive to pain. Prognosis poor. POA has dementia as well as veteran.

brother in Wxxx has Alzheimer's dementia and is the Power of Attorney. Continue ventilator support pending treatment decisions by family. Agree with use of opiates and benzodiazepines as needed for comfort. Consider bowel regimen if GI motility is impaired by opiates.

19 C19 is a 69-year-old WM veteran with history (Hx) of chronic schizophrenia. He is medically noticeable for HTN, chronic anemia, hyperparathyroidism, obesity, hyperlipidemia and PD. Recently found to have carcinoma of unknown primary origin with liver metastasis; also cognitively very impaired probably due to delirium. His oncologist essentially recommended supportive and comfort measures only given lack of therapeutic options in this case. He has been transferred to ECRC(2-2) for this purpose. Need ethics consult related to decision not to initiate any type of artificial feeding

1) Agree to recommendations of medical team for supportive/comfort measures only.
2) No artificial feedings, such as NG tube, PEG, are recommended; no clear evidence that they would prolong or increase quality of life (QOL); actually create more risk of complications such as aspiration.
3) Considering severity of his conditions, no active/curative interventions should be attempted; including any interventions causing discomfort, such as injections. However, injectable medications may be given for severe agitation associated with delirium. This is to insure the safety of patient and others.

20 The Blood Usage Committee referred this case for advice on notification of veteran of potential exposure to variant Creutzfeldt-Jakob disease (vCJD) due to the donor of blood having spent time in a vCJD area.

1) He is surgically and psychiatrically stable, should be able to comprehend nature of the situation related to his blood transfusion. EC finds no clinical evidence that disclosing potential exposure to vCJD would be harmful to patient.

Table 11 (Continued)

| | | |
|----|---|---|
| | | 2) Advise that Dr. Wxxx, should inform C20 even though the likelihood of his exposure to vCJD is theoretical at best. |
| 21 | Veteran's care question for patient with end stage lung cancer with metastatic diagnosis, unable to give consent or make decisions. No family involved, Extended Care Rehabilitation Center (ECRC) will perform ethics review. Patient is currently under palliative care. Follow up with ECRC. | Patient has Living Will dated 5/29/02 stating in event of incurable disease, his physician can make medical decisions on his behalf. Exhaustive search conducted to find his sister proved futile. Patient's mother is deceased. EC recommends: 1. Honor patient's living will dated 5/29/04. 2. Provide comfort care only. 3. It is not appropriate to draw labs. |
| 22 | 57 year old veteran previously at VAMC for chronic schizophrenia; recent cervical spinal cord injury resulted in paralysis; had three intubations in past month. Discussed at length with father, only living relative, on 3/9/2004. He is unable to make decision, asked VAMC do what's best for patient. Doctor explained he could not make decision and would discuss with VAMC EC regarding potential need for PEG and Tracheostomy and further discuss with family once a decision had been made. Need EC consult. | 1. Proceed with placement of Tracheostomy to protect his airway. 2. PEG should be placed for long-term nutritional support. 3. Therapy should be initiated to maximize functional ability. 4. Attempt should be made to have father consider accepting guardianship to facilitate medical decision making in the future. |
| 23 | 74 year old veteran, 100% SC with Schizophrenia has mass on his right kidney, presumptively renal cell carcinoma. He is | Consensus EC was to assist the family in making a decision as to whether or not patient should have recommended surgery. |

Table 11 (Continued)

scheduled for extensive and serious surgery. He is opposed to surgery and responded that surgery has already been performed. Difficult to determine if patient understands his condition or has capacity to make decision about procedure. Veteran's next-of-kin would like him to have the surgery, though there may not be complete consensus among the family members. The next-of-kin (NOK) are unsure if they should go against his wishes and force him to have the procedure. There is no court appointed guardian at this time.

EC member to contact family and offer an interdisciplinary family conference to help family make a decision.

24

C24 is a 74 year-old, 100% SC veteran who resists podiatry care necessary to keep him ambulatory and pain free. Caregivers are hesitant to order inpatient intervention due to his resistance, but concerned that his needs be met in an appropriate setting.

Encourage family to pursue guardianship. Also, encourage providers to seek further assistance in laying out risks associated with surgery. Have provider do a surgery consult with Dr. W to identify risks. Such information will be helpful when guardianship is established, unless otherwise considered by family, for treatment and care of veteran.

25

Staff doctor requested review of patient's current physical condition which included futile care for the past four months at VAMC following surgery. Doctor spoke with patient's son on Friday Oct. 12, 2007 and explained patient's condition. Doctor requested EC review case and make a

1. Family meeting with treatment team
2. Withdrawal of care – provide comfort measures only
3. No escalation of care at this point
4. Stay the course

Table 11 (Continued)

recommendation to clinical treatment team
and meet with family if needed.

Veteran is refusing picc line for IV
Antibiotics; was recently committed for
forced medication order and to pursue
guardianship. He has osteomyelitis and is
now in need of long-term IV antibiotics. His
family has had very minimal contact and
involvement with veteran due to his long
history of paranoid/delusional behavior.

1) Veteran's living NOK, brother, should be
re-contacted and informed as to the gravity
of the veteran's medical condition and try
again to get his decision to accept or reject
doctor's recommendation for treatment via
telephone consent for treatment.

2) In the event that the NOK refuses to aide
in decision making then attending doctor
consult with his Service Line Chief and
Chief of Staff concerning the protocol for
forcing medical treatment in this case.

3) Unit social worker to seek immediate
council from the local division of the
Department Of Social Services, concerning
emergency *guardian ad litem* or other
surrogate.

4) Social worker to seek information from
local agency regarding legal guardianship
process.

5) EC available to meet with brother if
necessary to reinforce attending doctor's
position; also available to meet with in-
patient staff for any follow-up as requested.

26

Note. EC indicates Ethics Committee

All entries were taken from Computerized Patient Record System (CPRS) then edited to present abbreviated information, while maintaining all key information.

CHAPTER 4 – STUDY 1 – Veteran-Formal Caregiver Relations

Main study one explored formal relational processes within the Veterans Affairs Medical Center (VAMC). Interactions of interest were between formal, professional caregivers (e.g., doctors, nurses, chaplains, and social workers), and between formal caregivers and veteran patients. The focus was on ethical concerns relevant to resolving veterans' healthcare crises. The unit of analysis was caregiving relationships, with particular focus on relational meaning and decision making processes. The research was guided by a social structural symbolic interaction (SSSI) theoretical framework.

To review, the main research question was, how does case documentation and documented processes of resolving ethical dilemmas in institutional healthcare for veterans reflect relational ethics? As explained in chapter one, relational ethics is generally defined as perceived fairness of interpersonal give and take (Boszormenyi-Nagy & Krasner, 1986; Van Heusden & Van Den Eerenbeemt, 1987), with fairness described as balancing earned entitlements and obligations (Hargrave & Pfitzer, 2003; O'Neill, 2002). In healthcare, relational ethics is also conceived as a *third entity* between interacting persons, a *relational or ethical space*, that required attention and nurturance (Bergum & Dossetor, 2005). Study one approached the research question by focusing on caregiving relationships internal to the VAMC and excluded involvement of informal caregivers such as veterans' family and friends.

Study one to follow is Act I of a two-act production and explained ethical relations as facilitating identification of actors with the ability to get things done, then casting them in primary supporting roles. Since the veteran main character's agency had been compromised to some degree, either mentally or physically, other actors needed to step forward to help. Some identified agent or agents had to decide what was to be done to take care of our ailing main character. If the veteran in our caregiving play regained effective agency, the supporting player or players could return to a less prominent role.

Documented VAMC caregiving relations of particular interest discussed ethics, caregiving, and once the core category emerged, agency. Agency emerged as the core conceptual category and veteran's agent as the most salient role. Agency meant that veteran patients could make choices and act on those choices in ways that impacted their care. When veterans' agency was physically or mentally compromised formal caregivers' roles as veteran's agents became

more salient. Study one substantive theory posed that relational ethics in caregiving for veterans was the **dynamic process of clarifying agency**.

The four-stage grounded theory methodology (GTM) applied in this research continued academic research trajectories in three major areas, ethics, caregiving, and agency. After reviewing the relevant literature, data analysis and substantive theory development, applying GTM (see Table 6 in Chapter Three) is presented. All references to patients use only case numbers (e.g. C4, C16, C19, etc.) to maintain veterans' confidentiality.

Study One Literature Review

Ethics literature. Ethics and relational ethics in VAMC caregiving is part of the larger context of general and clinical bioethics. This exploration of interpersonal interactions internal to the VAMC attempting to resolve ethical dilemmas in caregiving takes up challenges presented by Pellegrino's (1993) metamorphosis of medical ethics.

Pellegrino and others have noted that the delivery of institutionalized healthcare, including VAMC systemic care, profoundly changed in the latter half of the twentieth century. Growing market and bureaucratic influences steadily overshadowed ethical agendas of researchers and healthcare practitioners, importance of community to human development, and needs for meaningful relationship (Bergum & Dossetor, 2005). In addition, modern cognitive bioethical approaches did little to guarantee ethical relational behavior in caregiving.

Pellegrino (1993) described medical ethics as having four overlapping historical periods, which produced perspectives still exerting influence in healthcare delivery. The first and longest was the *quiescent* period, lasting some 2500 years. The second period, *principlism*, brought more systemic and objective perspectives of moral philosophers to the fore. He cites Beauchamp and Childress (1989) as best synthesizing these precepts into four principles that have impacted caregiving and healthcare to this day; nonmaleficence, beneficence, autonomy, and justice. The first two principles are synonymous with traditional Hippocratic obligations; beneficence, to always act in the best interest of patients, and nonmaleficence, to avoid doing harm.

The other two, autonomy and justice are somewhat antithetical to traditional caregiving ethics and have attracted the attention of numerous scholars (Gilligan, 1982; Hollway, 2006; Tronto, 1993). These scholars advocated for a care voice (Gilligan), an ethic of care (Tronto), and questions concerned with the capacity to care (Hollway). These voices will be discussed in the caregiving literature.

Lack of consideration for autonomy was one of the primary postmodern objections to traditional Hippocratic ethics, in that it gave no room for patients to participate in caregiving decisions on their own behalf (Gilligan, 1982). Patients have recently been given more autonomy through the process of informed consent, emphasizing privacy and self determination (Carse, 1996). Justice, the fourth principle, was most removed from traditional ethics; but with current disparities in distribution of caregiving and healthcare services it has moved to the forefront of medical and caregiving ethical concerns (Pellegrino, 1993). This is especially problematic in the Veterans Affairs medical care system which is experiencing escalating need for care and continued limitations of resources available to provide essential healthcare (United States Government Accountability Office [GAO], 2007).

Postmodernist movements of the 1960s led to a third period of *antiprinciplism*. This period was characterized by numerous criticisms of the four principles including, being too rational and abstract, too far removed from actual moral choices, and ignoring crucial personal issues such as character, culture, history, and gender. His fourth period was one of *crisis*; the one we remain in as of the time of this research. The crisis included the dangers of relativism and subjectivism if medical care and bioethics were left without principles and obligations. He proposed that what was needed was a way to link ethical traditions with contemporary moral psychology.

This study attempted to act on the proposition that *principlism* needs supplementation (Bergum & Dossetor, 2005; Gilligan, 1982; Hollway, 2006; Tronto, 1993). However, Pellegrino and others point out limitations of virtue-based theories as relying too heavily on the character of the agent, as crucial to producing ethical behavior, and for being too personal, private, and prone to significant individual variance in defining virtuous persons. Casuistry offers a compliment to the four principles that focuses on particular cases and concrete situations, such as the veterans in this study. Experienced-based casuistry does not deny the importance of principles and provides a valid method for case analysis, but may not be a consistently reliable guide to general moral theory and practice.

From this researcher's perspective, in-depth case analyses offered the potential to develop grounded theory. The argument was that casuistry, when combined with emphasis on relational ethics, offered compelling potential for, and did in fact, adequately frame substantive ethical caregiving theory. Despite concerns about dependence on the character of agents, the reality of

caregiving as experienced by veteran patients in this research confirmed the centrality of agency in meeting patient's needs. The emergence of veteran's mental and physical capacity concerns explicitly required formal caregivers and ethics committee members to act as agents on veteran patient's behalf, given the lack of meaningful family involvement in many cases.

The ethics of caring offered a convincing adjunctive alternative, as a prime motive of healing relationships (Bergum & Dossetor, 2005; Carse, 1996). However, Pellegrino argued that the term caring is subject to a wide variety of interpretations and needs some grounding in rules or principles to offer any trustworthy guide to specific decision-making in caregiving.

Alternative ethical bases can complement but not replace ethical guidelines and principles. Note that none of these views focus explicitly on relational ethics in caregiving. This GTM research grounded the meaning of ethical caring in the day-to-day documented relational context of the VAMC. Study one explored desired care, as expressed in advanced directives, living wills, and veteran's expressed wishes, compared with care actually delivered by formal caregivers.

This study expanded Pellegrino's fourth proposition that ethical principles need to be grounded in the physician-patient relationship. Our current age of treatment teams and multidisciplinary approaches to healthcare required an expansion of the relational lens to include the entire field of interpersonal relationships that surround formal caregivers and care recipients (Bergum & Dossetor, 2005; Carse, 1996). Focus on physician-patient relationships, to the exclusion of other formal relationships and interactions, proved too narrow a lens in developing substantive theory. The category of formal relations explored both staff to staff interactions at the VAMC and relations between formal caregivers and veteran patients.

I accepted Pellegrino's fifth proposition that medical ethics held out the best hope for a better grounding of principles, rules, and virtues. The universality of our ultimate human frailty was dramatically played out for veterans in the VA Medical Center. Finally, he posed real life caregiving questions, "What is the right and good thing for me to do? What is good for patients and what kinds of actions will achieve it?" (Pellegrino, 1993, p. 1162).

His suggestions for answering these questions pointed toward clinical bioethics that focused on the realities of moral choice as they were faced in caregiving crises. Exploration of medical care at the VAMC offered fertile ground for examining ethical behavior in health care (Gordon & Benner, 1996). Pellegrino (1993) stated that the medical caregiving environment provided the empirical research and evaluations that any theory of ethics needed if it was not to

legitimate practices that distorted realities of the physician-patient relationship as it actually existed. By grounding research in documented case data, this researcher sought to avoid distorting the realities of the varied web of relationships that surrounded veteran patients. This grounding was especially important regarding ambiguous ethical issues, where veteran's preferences were unclear and their personhood compromised.

Caregiving literature. In social structural symbolic interaction (SSSI) terms, the degree to which roles can be made and not just played indicated potential for larger social structural change. The role of caregiver framed exclusively by principlism and moral reasoning was challenged by Gilligan's (1982) gendered critique of Kohlberg's (1976) stages of moral reasoning. She raised serious questions about how the role of caregiver is played in gendered differences of moral reasoning. In contrast to the voice of justice, Gilligan posed a voice of care beginning a new conversation about how the role of caregiver is played.

Tronto (2001) continued the conversation from a political perspective and suggested a four-phase ethic of care with phase one as attentiveness or *care about*, phase two as responsibility or *care for*, phase three as competence or *care give*, and phase four as responsiveness or *care receive*. She argued that dividing the world of care into public and private spheres tended to devalue private care and suggested that our resistance to valuing the role of care might be related to avoidance of thoughts about death. She explained that no matter how well we care for ourselves and others, we ultimately die, as was the case for 18 of the 25 veterans in this study.

In discussing care for elderly persons, Joan Tronto talked about the "myth of our own invulnerable autonomy" and suggested, "Embracing care as a part of human life, recognizing its role in creating interconnections and relationships of receiving and giving over a lifetime..." (Tronto, 2001, p. 67). Veterans in this study presented the stark reality that invulnerable autonomy is a myth. As their agency faded, VAMC staff did their best to act as agents for the best interests of veteran patients.

There has been recent debate concerning the validity of an ethics of care. One of the clearest statements concerning that debate was provided by Sasha Roseneil:

Many feminists have expressed reservations about the whole-hearted embracing of an ethics of care, regarding it as over-reliant on a model of care developed from thinking about the fundamentally gendered care practices of mothers for their children, and fearing

that it brings with it a diminution of concern about the ethics of justice and social equality... We should be wary that advocating an ethics of care might involve endorsing a model of self which is so fundamentally relational that any sense of individuality, separateness, and capacity to act autonomously is negated (Roseneil, 2004, p. 414).

In this study, even though veterans and formal caregivers collaborated with one another, the capacity to act effectively as an agent in the VAMC context resided in individual veterans, doctors, nurses, social workers. To whatever degree veterans were able to act as agents on their own behalf, there were other actors on stage. Individual choices and actions by individual actors reflected their capacity to care.

The capacity to care was assumed when this research began. However, the eight descriptive statements of SSSI (see Table 3, Chapter 2) informed the study in noting the power of the VAMC structure to name and classify professional roles, define what was and was not considered an ethical dilemma, and the degree to which roles could be modified in the caregiving context. Given the impact of role designations and expectations, provided and reinforced by the surrounding social structure of the VAMC, some consideration of the capacity to care was required.

Hollway (2006) examined rather than presumed the capacity to care. Tronto (1993) had moved the debate away from the mother-child paradigm and into the political realm, whereas Hollway pointed out that care was an inherently relational term and retained the mother-child model, expanded to include other parental and caregiving figures nurturing children. She stated the prospect, as did the substantive theory developed in this study, that “It should still be possible to transcend the binary between autonomy, independence and the ethic of justice on the one hand and relationality, empathy and the ethic of care on the other in understanding the capacity to care” (Hollway, 2006, p. 16). The dynamic process of clarifying agency and identifying effective agents in this research provided one span to bridge that binary.

Agency literature. From a psychosocial view, agency in this study was understood in the context of relationships embedded in the VAMC. However, agency has often been viewed in the American cultural context as much more self determined.

To say that persons self determine... is to say that they perform...acts and that they have plural voluntary control over their doing so and doing otherwise [right up to the very point of acting]. Agents have plural voluntary control when they are able to do what they

will to do, when they will to do it, on purpose rather than by accident or mistake, without being coerced or compelled in doing, or willing to do it, or otherwise controlled by other agents or mechanisms. (Kane, 1998, p. 191)

This description of agency seems unrealistically over-determined and was not apparent in the research. Many of the veterans possessed the property of agency but in varying degrees and seldom to the point that they could function independently of formal caregivers. The understanding of agency gained from the data was aligned with the conception of agency as embedded and situated i.e., environmentally bound, yet emergent in social, cultural, and historical contexts; part of a very real physical and biological world (Martin, Sugarman, & Thompson, 2003).

In a similar vein, Bandura (2001) has consistently resisted reductionism in psychology and described agency as including the power to initiate purposeful action. He espoused the belief in personal efficacy as essential to agentic action and that such belief depended on functional relationships. Again, the term agency was understood in relational context. In nearly perfect congruence with symbolic interaction (SI) and social structural symbolic interaction (SSSI) perspectives, Bandura (1986) stated

people are both producers and products of social systems. Social structures...do not arise by immaculate conception; they are created by human activity. Social structures, in turn, impose constraints and provide resources for personal development and everyday functioning. But neither structural constraints nor enabling resources foreordain what individuals become and do in given situations. (p. 6)

Thereby, formal caregivers and veterans in this research remained ethically responsible for their actions.

Study One Data Analysis

Study one explored a total of 78 primary documents for 13 selected veteran cases shown on pages 92-93. The analysis produced a total of nearly 300 codes, 17 code families, 80 memos, and 4,823 code-related quotations. All 25 veteran cases in the research were coded, categorized, and analyzed in study one. However, 13 of the cases were more relevant to development of substantive theory given the focus on formal caregiving relationships. In these cases, formal relationships internal to the VAMC appeared to be more important to ethical dilemma resolution

processes than formal-informal interactions. Veterans' family members, friends, and significant others were less involved, if at all, and therefore less significant to ethical resolutions.

The choice to exclude formal-informal caregiver interactions in study one provided a means of partialling out family and significant other involvement, which complicated already complex processes being explored. Family and significant others, especially spouses, had every right to question and influence veterans and formal caregivers to consider their needs and the impact of care decisions on them. However, the strategy was to focus specifically on interactions internal to the VAMC. In addition, study one did not put emphasis on the fact that many interactions included both communication between formal caregivers and between those caregivers and the veteran. These three-way interactions took place when medical teams made treatment rounds. Again, the focus on formal-formal caregiver and formal caregiver-veteran interactions helped clarify ethical resolution processes and substantive theory development.

In theatrical terms, including the family meant more and varied actors on stage. They lacked the specialized language skills and knowledge of the formal players. In addition, they were only indirectly experiencing the pain and trauma of the veteran patient. They distracted attention from the primary actors; those in the roles of formal caregivers and veterans on the VAMC set. Veteran's significant other actors were asked to wait until Act II to participate.

Another observation in reviewing the data and talking with Dr. Kim was that family visited veterans on varying schedules. Worst case no one visited the veteran and best case meant daily visits that totaled 10-12 hours weekly. Therefore, veterans were spending time alone or with formal caregivers somewhere between 156 and 168 hours weekly, a factor of 13 to 17 times more hours spent with the patient. Although it took intentionality to keep family out of study one analysis and helped understand the dynamics of interactions clarifying agency at the VAMC.

Again, all 25 cases contained data relevant to the formal interactions of study one. However, emphasis on these 13 allowed for a more in depth discussion of the analyses leading to development of substantive theory, as opposed to a more cursory presentation of all 25 cases.

The selected/highlighted study one cases, with brief case descriptors, were:

- | | |
|-------------------------|--------------------------------|
| C4 – Thirsty AMA | C6 - Motorcycles and Narcotics |
| C10 – Risk and Danger | C13 - Stop Treatment |
| C15 – Living Will | C16 – Different Opinions |
| C17 – Internal Solution | C18 – Only Pain |

C19 – Comfort Only

C20 – Blood Dangers

C21 – Lost Family

C22 – Cannot Decide

C26 – Refused Care

Analysis of data using *ATLAS.ti* reinforced selection of the 13 highlighted cases as shown in Table 12. Table data focused on nurses, social workers, and doctors since they recorded nearly all of the meaningful psychosocial documentation regarding contact with veteran’s family members and significant others.

Note that all coded data percentage comparisons, except for REL:FORML:NURS-FAM (formal-informal relations between nurses and family members), which is split evenly between the two studies, confirm the relative importance in study one of formal relations internal to the VAMC over formal-informal relationships that include family and significant others. Also, the coded data percentages confirm the relative importance of formal-informal relations in study two. This is qualitative, not quantitative research. However, cases documentation was analyzed in Table 12, according to the volume of data relative to each study, as a means of evaluating the researcher’s subjective selection of cases for each study through case familiarity.

Table 12

Comparison of Study One and Two Coded Data Quotations

| Relational Codes (Informal and Formal) | S1 Data (13 Cases) | S2 Data (12 Cases) | ^a S1% of Total | ^b S2% of Total |
|---|-----------------------|-----------------------|------------------------------|------------------------------|
| REL:INFORML:FAMILY:INVOLVED | 158 | 234 | 40.3% | 59.7% |
| REL:INFORML:SPOUSE | 84 | 164 | 33.9% | 66.1% |
| REL:FORML:NURS-FAM | 18 | 18 | 50.0% | 50.0% |
| REL:FORML:DOC-FAM | 89 | 161 | 35.6% | 64.4% |
| REL:FORML:SW-FAM | 27 | 40 | 40.3% | 59.7% |
| REL:FORML:NURS-VET | 59 | 16 | 78.7% | 21.3% |
| REL:FORML:DOC-VET | 383 | 215 | 64.0% | 36.0% |
| REL:FORML:SW-VET | 45 | 10 | 81.8% | 18.1% |

Note. S1 and S2 Data Columns show total number of quotations linked to the indicated code.

All Relational Codes indicating family and significant others involvement were prefaced with REL:INFORML; And, for formal-informal and formal caregiver-veteran relational codes with REL:FORML.

FAMILY:INVOLVED coding meant any kind of involvement by any family member or significant others in the veteran's case and SPOUSE meant any involvement by veteran's spouse, whether positive or negative in nature. Hyphenated codes, NURS-VET, NURS-FAM, DOC-VET, DOC-FAM, SW-VET, and SW-FAM indicated interactions between doctors and veterans, doctors and family, and so on.

^aGiven the extra case in study 1 all percentage figures in this column may be somewhat overstated

^bGiven that there was one less case in study 2 than in study 1 all percentage figures may be relatively understated

Stage one GTM analysis for C26. Stage one analysis (see Table 6, Chapter 3, page 38), applying grounded theory methodology (GTM), began with veteran C26 (Refused Care). This veteran refused care important to taking care of serious infection and was estranged from his family due to his long history of paranoid and delusional behavior. The four stages of GTM analysis (see Table 6 in Chapter 3) for C26 proceeded as follows:

Stage one opened up the data, created code names, and developed concepts. It started with line-by-line coding. Coding of the following two Advanced Directive documents revealed concerns related to VAMC staff communication with veteran C26.

03/11/2008 13:16 Local Title: PATIENT ED RE: ADVANCE DIRECTIVE

Standard Title: ADVANCE DIRECTIVE DISCUSSION

An Advance Directive has been discussed with C26.

The following was the outcome of the discussion:

Patient does not want additional information.

Patient does not have an Advance Directive and would like more information from our Social Worker.

The patient has an Advance Directive and it was REVIEWED with veteran and/or surrogate. No changes to current Advance Directive.

Information given to patient to review, no action requested at this time.

Due to Dementia veteran is not capable of executing an Advance Directive at this time; The VAMC is currently pursuing guardianship for veteran.

Signed by, LCSW (Licensed Clinical Social Worker)

And, part of a second Advanced Directive entry documented just over five months earlier, indicated that C26 did not want additional information.

10/30/2007 16:25 Local Title: PATIENT ED RE: ADVANCE DIRECTIVE

Standard Title: ADVANCE DIRECTIVE DISCUSSION

An Advance Directive has been discussed with C26.

The following was the outcome of the discussion:

Patient does not want additional information.

Signed by, LCSW (Licensed Clinical Social Worker)

A sampling of codes for the two preceding documents included, AD:DATE OF ADVANCE DIRECTIVE; AD:DISCUSSED W/ VET; AD:DISC W/VET W/O CAPACITY?; AD:SW; AD:IN CHART; AD:GUARDIAN DESIGNATED?

In November of 2007 an interdisciplinary medical team entry (shown below) documented that, "C26 has multiple year history of progressive dementia picture," raising the question of whether or not he could even understand the nature or significance of the offer for information. At the time this was coded the researcher recorded this memo, "Veteran supposedly does not want info; however, within a couple of weeks veteran was assessed as having a multiple year

history of progressive dementia, and a little over five months later as too demented to discuss advance directives? Inconsistent entry?”

Line-by-line coding of study one cases produced nearly 300 codes, grouped into 17 code families, and 4,823 related quotations. As a specific example of code development leading toward concepts related to compromised capacity, line-by-line coding of this and other Advance Directive documents developed 26 codes and 396 coded quotations in study one related specifically to Advanced Directive issues such as power of attorney, which formal caregiver interacted with veteran, and care preferences. These 26 codes were grouped into a code family for Advanced Directives prefaced by *AD*. Comments were recorded in the software for code families to clarify data contents.

Comment: Advance directives or living wills represent the wishes and will of the veteran. This is an indication of how forward looking the veteran might be regarding critical or end of life care. Given interest in individual rights the wishes of the veteran should mandate nature of care when such documents are in place. However, these directives are often complicated by issues of capacity and medical care personnel agendas and motivations.

Here is a sampling of the 26 codes created in this family of codes:

[AD:DISC W/VET W/O CAPACITY?]

[AD:DISCUSSED W/ VET]

[AD:DNR]

[AD:DNR:CARE WITHHELD]

[AD:FULL CODE]

[AD:GUARDIAN DESIGNATED?]

[AD:HONORED]

[AD:VET WANTS INFO]

[AD:VET WANTS NO INFO]

The first code listed, [AD:DISC W/VET W/O CAPACITY?], indicates an advanced directive that, according to the third line of the first document presented, was discussed with the veteran. However, lines 12 and 13 clarify the fact that the veteran lacked the mental capacity to have discussed the document. These inconsistent and contradictory entries appeared in many of

the cases in study one. Veterans without capacity were documented as being involved in the process, as shown in the following interdisciplinary team note for C26.

LOCAL TITLE: INTERDISCIPLINARY TEAM PATIENT TREATMENT PLAN

STANDARD TITLE: TREATMENT PLAN INTERDISCIPLINARY NOTE

DATE OF NOTE: NOV 15, 2007@08:05

The following treatment team members collaborated in the development of the patient treatment plan: Attending, Resident, Psychologist, Social Work, Veteran.

Dementia- C26 has multiple year history of progressive dementia picture, causing loss of independence and putting vet at risk of harm by failure to care for self (i.e., wandering, environmental exposure)

Goal is to help C26 understand implications of dementia, so that vet will be more amenable to treatment. Vet continues to have very limited insight into his dementia, sees no need for care ("you're hypnotizing me"). Team will continue to attempt to help vet recognize his dementia. Goal moved to 11/30/07

This and many other examples of veterans documented as participating in collaborative treatment planning meetings, consultations, or assessment interviews seemed misleading to this researcher. However, it also indicated a consistent pattern on the part of VAMC staff to include the veteran and his desires as part of formal caregiver interactions. The probability of such collaboration being effective raised ethical questions; as does the possibility of a veteran with years of progressive dementia recognizing his dementia. Line 13 also mentioned that the VAMC was pursuing guardianship for the veteran. Early coding, especially of Advanced Directives, along with literature review and reflection, developed concepts of veterans' compromised capacity and formal caregivers having to act on patients' behalf.

Stage two GTM analysis. Stage two analyses for C26 used concepts from stage one to further abstract relational ethics issues, and created categories. Properties and their dimensions were identified. The following "Brief Clinical History" from a CPRS ethics referral provided a good example of documentation that facilitated stage two analyses.

LOCAL TITLE: ETHICS REFERRAL

STANDARD TITLE: ETHICS NOTE

DATE OF NOTE: NOV 16, 2007@16:17

C26 is a 75 year old Caucasian male with mild to moderate dementia, associated paranoia regarding healthcare providers and current lower extremity cellulitis (*Skin Infection*) and

edema (*fluid trapped in body*) with high risk for developing DVTs (*Deep Venous Thrombosis*). He is refusing all recommended care. Veteran was admitted to acute psychiatry following sudden discharge from a Health and Rehab Center to a local Rescue Mission. While there, he was determined incapable of caring for self or living independently and was subsequently transferred to the VAMC. Veteran currently ambulates with a wheelchair and depends on nursing staff for essential care needs. He has developed severe cellulitis and edema of left lower leg and is refusing antibiotics and other critical care measures. He is at high risk of developing potentially fatal DVT. C26 has mild to moderate cognitive impairment with significantly impaired insight and judgment into current clinical circumstances. His brother has been contacted and essentially his family members indicate no desire to participate in his care or be responsible for making healthcare decisions on his behalf.

Note. Potentially fatal deep venous thrombosis (DVT) is a condition where blood clots form in veins deep inside the body.

A sampling of codes for the preceding document included, DG:AGE; DG:RACE; PSYCHOSOC:MH:PARANOIA; PSYCHOSOC:MH:DEMENTIA; REL:FORML:COMM/BEHAV PROBS.

The unwillingness of family to be involved in this case placed emphasis on interactions between formal caregivers and the veteran. The veteran's dementia-related paranoia regarding health care providers complicated caregiving relational ethics regarding how coercive VAMC staff should be in order to save the veteran's leg and perhaps his life.

Stage two addendum data entry issue. Another part of the research process was the recognition that significant relational and psychosocial data was recorded in addendums to various progress notes, consults, reports, etc. The following was a dated sampling of addendums, or footnote entries, concerning veteran C26 and the disposition of his case.

11/20/2007 ADDENDUM

STATUS: COMPLETED

Called local Health & Rehab Center and spoke to their Social Worker and Business office. They reported that C26 paid for his first month's stay but nothing more for the year he was there. Also said that they sent the Nov. SS check of \$640 back to the Social Security Office. In addition, he owes them \$32,764.13 and they have placed a judgment

against him. Reported this info to the above Ethics Committee meeting today also. Will f/u w/ calls to Family Service and DSS Adult Protection offices to begin process of seeking Guardianship for veteran's care.

Signed, LCSW (Licensed Clinical Social Worker)

11/21/2007 ADDENDUM STATUS: COMPLETED

We will need to consider use of antipsychotic in this patient. C26 continues to be delusional and as part of that delusion as been refusing any medications. At this time, unable to give any medications for his dementia or psychosis without patient approval. Guardianship proceedings are pending. May need to consider forced medication order for the psychiatric medications. Signed, MD (Medical Psychiatric Resident)

01/11/2008 ADDENDUM STATUS: COMPLETED

This morning I have spoken to Dr. L about C26 and Dr B has spoken to Dr. W regarding this patient. Patient is set to be transferred to ECRC (*Extended Care Rehabilitation Center*). Due to the difficulty of maintaining a level, and given that pt has been cooperative and compliant with care after administered and has not been agitated or required any medications for agitation, may discontinue BOS 3 (???). Continue to have C26 closely supervised, continue wanderguard (*departure or wandering alert system*), continue using behavioral techniques such as distraction and redirection, avoiding unnecessary confrontation. May use prn (*As Needed Medication*) haloperidol as detailed in note for agitation or behavioral disturbance. Signed, MD (Psychiatry Resident)

01/30/2008 ADDENDUM STATUS: COMPLETED

AS PER RECOMMENDATIONS, WILL DISCONTINUE SCHEDULED HALDOL (LEAVE PRN) & SWITCH TO RISPERIDOL LIQUID TO BE GIVEN IN FOOD/DRINK. WILL MONITOR FOR LESSENING OF DELUSIONS BUT AS PSYCHIATRY NOTED, THIS MAY VERY WELL NOT HAPPEN. AS PER DR. Lxxx'S REQUEST, HAVE ASKED THAT MS.F, SERVICE LINE CHIEF ASSIST IN PLACING OF ETHICS COMMITTEE CONSULT. BARRING A SUCCESSFULL RESOLUTION, AGREE AGAIN WITH PSYCHIATRY THAT C26 SHOULD AT

THAT POINT BE RETURNED TO A WARD WHERE HE CAN BE BETTER
MANAGED. Signed, PA (Physician Assistant)

Stage one and two analysis resulted in the exploration and coding of 173 addendums, for the 13 selected study-one cases. Many were of little consequence, but as the sample above for C26 showed, many contained vital information concerning formal caregivers and veterans interactions. It was difficult to determine why so much important information was recorded in addendums. Possible explanations were, thoughts or information that came to professional caregivers after main entries were written and entered into the CPRS, that the format of regular entry forms had no specific place for such information, or that formal caregivers were not clear on how to document certain content within the existing document formats.

Completion of stage two analysis. By the completion of stage two, a complex web of codes and categories had been developed. Categories of most significance were:

| | | |
|------------------------------|-----------------------------|--------------------|
| MENTAL HEALTH | MEDICAL CONDITION | ETHICS ISSUES |
| LIFESTYLE | ADVANCE DIRECTIVES | SERVICE CONNECTED% |
| EOL ISSUES | PAIN MANAGEMENT | PHYCHOSOCIAL |
| CAREGIVING | FORMAL-FORMAL RELATIONSHIPS | |
| VETERAN-FORMAL RELATIONSHIPS | | |

Analysis of the 13 highlighted cases produced seven categories, reduced and refined from 17 earlier data categories, shown in Table 13 on the next page.

Table 13

Study One - Stage Two GTM Analysis Categories

| Categories | Properties | Dimensions |
|---------------------|-------------|---|
| Veteran's Capacity | Mental | Mental = assessed capacity, dementia, severity of mental health diagnoses (bipolar, schizophrenic, paranoid, etc.), emotional stability; |
| | Physical | Physical = mobility, ADL (Activities of Daily Living) capability, medical condition, and prognoses |
| Formal Relations | Staff-Staff | Staff-Staff = collaborative or conflicted, level of agreement, trust levels, multidisciplinary factor (how many disciplines involved) |
| | Vet-Staff | Vet-Staff = collaborative or conflicted, recognition and validation of veteran as person, trust levels, appreciation/respect for expertise caregiver expertise |
| Veteran's Care | Desired | Desired = Conveyed in Advance Directives and Living Wills, and in interaction with VAMC staff |
| | Delivered | Delivered = Care provided and documented by VAMC staff |
| Veteran's Lifestyle | Healthy | Healthy = nutrition, daily activity or exercise, weight control, relations with VAMC staff |
| | Detrimental | Detrimental = poor diet, sedentary life, harmful habits (substance abuse, nicotine, etc.), poor weight control, emotionally cut off or aggressive i.e., social skills and relationship problems |

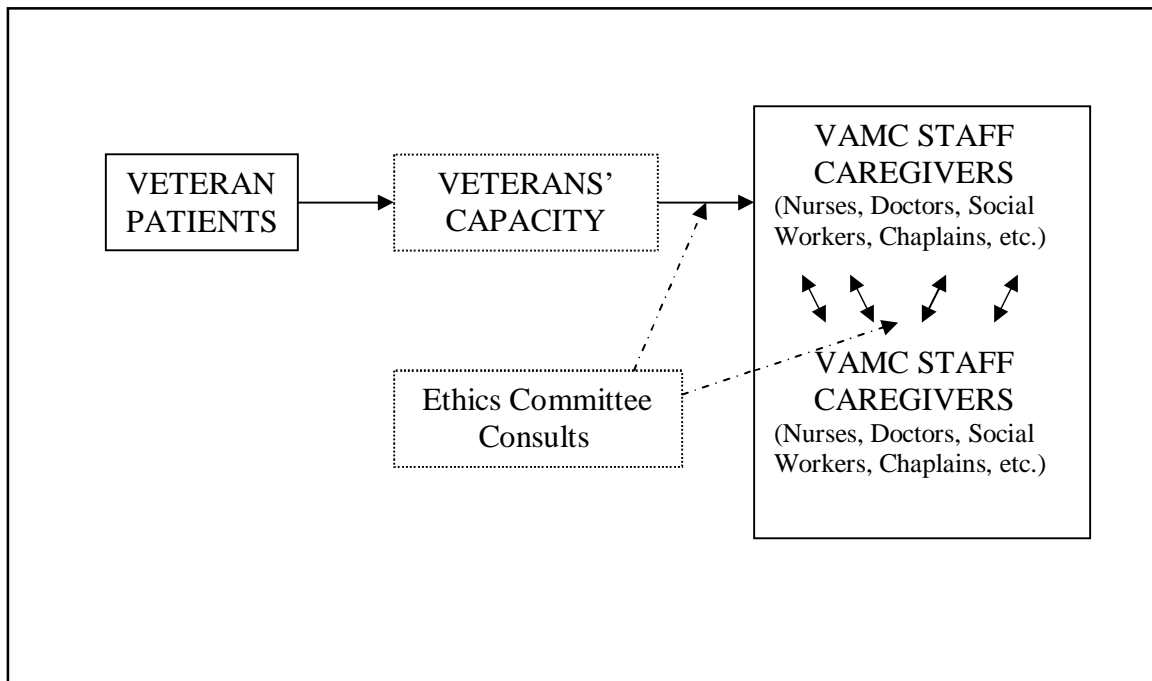
Table 13 (Continued)

| | | |
|--|-----------------------------|--|
| Ethics Issues | Ethical | Ethical = least restrictive care (veteran allowed to be as independent as possible), VAMC staff support veteran as a person, patient’s care preferences elicited and honored |
| | Ambiguous | Ambiguous = veteran’s preferences unclear, veteran’s personhood compromised, concerns with coercion or deception, ethics consult usually involved |
| ^a % Service Connected (SC) Rating | Service Connected (SC) | % Service Connected (SC) = Military service connected rating, based on veteran’s VA enrollment care priority, varies from 80-100% in the research population; 100% rating may impact veteran’s ability to have care wishes met |
| <u>Table 13 (Cont.)</u> | | |
| | Not Service Connected (NSC) | Not Service Connected (NSC) = care at VAMC not service connected, veteran pays co-pays for care with annual limits on total cost to veteran |
| ^b EOL Issues | Cure | Cure = Standard procedures and actions by VAMC staff to cure veteran’s medical problems, and may include full-code, aggressive testing, surgery, medications, and procedures |
| | Comfort | Comfort = Veteran’s condition terminal in less than 6 months, palliative or hospice care indicated |

^{ab}Dr. Kim shared his impression that in cases where veteran care was 100% service connected it was more likely that aggressive full-code care would continue, with heroic measures to cure vs. comfort, up to the very end of life.

Stage three GTM analysis. As study one moved to stage three analyses the data was reassembled, core axes identified, and linkages established between categories that clarified relational processes. Figure 1 below presented two primary communication channels representing documented relational processes. The horizontal channel was between veteran patients and formal caregivers, and the vertical channel between and among formal caregivers. In many cases, veteran's capacity impeded communications in the horizontal channel and ethics committee consults influenced communication in both channels. Table 13 categories of % Service Connected, Veteran's Capacity, Veteran's Care Desired, and Veteran's Lifestyle related to the horizontal channel. The Formal Relations category was conceptually split and explored respective channel communications. Ethics and EOL Issues categories were the subjects of communications and kept focus on the dynamics of changing case circumstances.

Figure 1. Study One - Stage Three Relational Processes



As reflection on the core category and data linking continued, it became obvious that assignment of the role of agent or the empowerment of agency was not a static proposition. Case circumstances in all the cases above were dynamic, as was the process of clarifying agency. An observation that case situations constantly change stated the obvious. However, the negotiation

of healthcare agency between veterans and VAMC staff in this study was dynamic, complex, and crucial to ethical resolution of veteran's healthcare dilemmas. The exercise of the combined agency of veterans and formal caregivers determined the details of day-to-day care and case trajectory.

Stage four GTM analysis. As GTM analyses transitioned from stage three to stage four a conversation with Dr. Kye Kim triggered thoughts that progressed towards the core category of agency; followed by selective coding, and explanation of processes and relationships that generated substantive theory for study one. He introduced the term *Shared Autonomy* as the way he thought about the process of ethics consultation. We spent some time discussing the concept. I left our weekly meeting with some ideas about how the term might connect to findings in study one. My understanding of autonomy at that point in time was essentially self governance. Analysis shifted, noting that some elements of autonomy could be seen as dispersed.

Agency and salience of the patient role. Reflection on the core axes in Table 13 and relational processes in Figure 1, along with analysis guided by SSSI theory of veteran's role commitment to being a patient, accompanying role salience and hierarchy, and social structural position of patient at the VAMC led to emergence of agency as the core category. The centrality of veteran's agency in the research recognized patient role salience as pivotal for all other categories. Agency is embedded in roles and if role commitment is very low or nonexistent in the role salience hierarchy then the likelihood of having any agency in the role of patient is unlikely. Further, from the perspective of social structural position, the designated role of patient impacts agency by promoting playing the role as expected, rather than trying to make or modify that role.

The feasibility and pilot studies raised significant ethical concerns in perceiving veterans, in their role as patients, as fully competent agents capable of acting on their own behalf as posed by Kane (1998). However, many veterans maintained varying degrees of agency. Patients in the research played two primary roles in the social structural context of the VAMC, veteran and patient. SSSI theory explained (see chapter 2, Table 3) that people act in context, conscious of roles; that role commitment depended on being a particular kind of person in one's social structural group; and that the degree to which roles could be made and not just played determined potential for social structural change.

The role of veteran was particularly salient for the study patients. All patients were veterans and 20 of the 25 veterans in this study served in time of war. According to a December

2007 Fact Sheet: Facts About the Department of Veterans Affairs, about 60 percent of all male employees at the VA are veterans. Overall, seven percent of veterans are female. Just over six percent (17,346) of the VA's 271,000 plus employees are female veterans. Over 24 percent of VA employees are disabled veterans and three have received the Medal of Honor, the highest military decoration awarded by the U. S. Government (VA, 2007).

Veteran's role commitment. Considering the social structural context of the VAMC, the veteran's role as patient should have been, and in most cases was, the most salient in case documentation. However, there were five cases (C4, C10, C16, C22, and C26) in study one where veteran's behavior was particularly resistant to the designation of patient. Role commitment to role of patient was problematic for these five patients. Also, as reported in the pilot study, both C2 and C9 seemed to indicate resistance to treatment, implying resistance to their role as patient. C2 may have been trying to pull out life support tubes, and C9 wanted to stop treatment and go home to die.

C4 analysis, role commitment and salience. In study one, C4 the *Thirsty AMA*, was thirsty much of the time. He consistently drank too much water, which exacerbated edema (fluid retention) problems similar to those mentioned for C26 above. C4 often acted against medical advice (AMA), and resisted his role as patient consistently as evidenced in the following staff physician data entry:

Note that abbreviations and VAMC terms are spelled out in parenthetical italic (*italic*) format.

C4 was unhappy with the thought of staying here indefinitely, with staying here at this time. The Ethics committee was asked to get involved. They suggested asking for neuropsych testing to determine his capacity for decision making. Hence the team started to work on d/c plans that C4 wants: to live alone, locally. It is noted that C4 asks to leave AMA (*Against Medical Advice*) when things do not go the way he wants. This can be a problem, especially when the regular care givers who know him are not on duty. Plus if we gave him an AMA discharge without lots of planning, meds, follow up, he would not last long (probably.) Hence we shall leave the order to TDO (*Temporary Detaining Order*) him if he insists on AMA discharge.

Temporary Detaining Orders were to keep resistant patients in the role of patient, at times against their will. This provides an example of the difficulty of making versus just playing the

role of patient. It also indicates the role commitment of the doctor in maintaining his position of formal caregiver with power over the veteran by means of a TDO.

Further, a nursing entry for C4 documented conflict and desire to leave the VAMC. Note that 'ALL CAPS' was the original document formatting.

WHILE MAKING ROUNDS, HEARD WATER RUNNING IN BEDROOM OF PT'S ROOM. FOUND PT WITH A STYROFOAM CUP FULL OF WATER. I TOOK THE CUP AWAY FROM PT AND SOME WATER SPLASHED ON HIS PJS. PT STATED THAT I THREW WATER ON HIM AND CALLED ME A BITCH AND STATED HE HATED ME AND WANTED TO SIGN OUT AMA. INFORMED PT THAT HE WOULD BE REPORTED AND HE BECAME VERBALLY ABUSIVE AND CURSING STAFF. PT ALSO SAID THAT HE BETTER NOT BE RESTRICTED TODAY. PT TO BE RESTRICTED TODAY.

C4 case documentation went on to log numerous conflicts with VAMC staff, expressions of desire to leave the VAMC against medical advice, and the desire to be discharged to live alone. The above interaction was later understood as a struggle over agency; the veterans desire to not be restricted so he could go on an outing with other veterans and the nurse putting him on restriction for verbally abusive behavior.

C16 analysis, role commitment and salience. C16 was often combative and expressed the desire to leave his role as patient and go home, as he finally did. Some data entries follow. First, one by a staff physician.

The patient was admitted and was initiated in Physical Therapy. The patient did fairly well with this, rapidly becoming independent with transfers. Additionally, by last discharge, the patient was independent on a walker. The patient became very angry at least twice during admission, necessitating calls to security but was calmed down after Security Officers appeared at bedside. The patient was seen by Psychiatry who felt that the patient had Borderline Personality Disorder. Psychiatry felt that the patient was competent to leave as long as he had a plan in place if he decided to leave the hospital against advice.

A second entry for C16 by a staff psychiatrist:

Like to stay at home, and does not like to be around with people, as he does not trust people, and believed that people talked bad things at his back. Has a lot of anger toward

VAMC and local hospital. He states that all local hospital did was giving him prescription instead of medications, and he has not money to buy meds. States that he has not nobody caring about him. He has one son who is not close to him. He states that no doctors in the hospital care about him. Denied any SI/HI (*Suicidal/Homicidal Ideation*), or any hallucinations. Of the note, he states that he does not want to go to assistant living, and he thinks that he is able to take care of himself. However, per record, recently, pt was found with no food in his apartment and extensive gangrene, and refused medical treatment, which lead to Adult Protective Services involvement.

Finally, an entry for C16 by a VAMC physician:

On September 20, at eight o'clock in the morning, the nursing staff noted that the patient was not in his room. They were not able to locate him prior to that. He manifested some anger towards the nursing staff. We were notified at 8:30 in the morning and we tried to look for the patient in the hospital. We also asked the operator to announce this in the overhead pager, but the patient has not responded and also his belongings were not in the room. The patient left AMA and no prescriptions and no further follow up was done before he left.

C10, C22, and C26 analysis, role commitment and salience. In addition, patients C10, C22, and C26, as previously indicated, at some point during their time in the role of patient had little or no role commitment. A documented example for each case follows. C10 offered the most dramatic and troubling case of all due to a history of sadistic and pedophilic tendencies and behaviors.

LOCAL TITLE: ETHICS TEAM FOLLOW-UP

STANDARD TITLE: ETHICS NOTE

DATE OF NOTE: JAN 06, 2006@12:35

Disciplines present: Attending, Dr. Nxxx, Nursing: Sxxx, RN, Jxxx, RN, NM; Lxxx, RN, MD Psychiatry, MSW and Ethics Team Members: Kxxx, Jxxx , and Rxxxx.

From review of the record and from interviews with staff present at the meeting today it is clear that the patient presents a danger to himself, the staff and the community.

Working through their service line chief and in cooperation with the regional council's office, staff has attempted to locate a facility that would be able to contain the patient while providing the treatment that he needs. So, far, they are unsuccessful. At this time,

they are preparing for the expiration of the commitment (*forced hospitalization*) (70 days from now). Furthermore, C10 has made aggressive comments and overtures to members of the staff as well as an elopement attempt so that the staff are hyper-vigilant and feel that further measures to prevent harm to themselves or other patients are required.

The first observation was that the number of attendees at this ethics committee follow up meeting was an indication of the severity of the ethical concerns related to C10. At this point in the case it was clear, given the elopement attempt, that the veteran would not have remained a patient without a commitment order. In this case, coercion was warranted given the potential danger to the community. C10's case will be presented in further detail later in this analysis.

The following Discharge Summary for C22 clearly documented his resistance to the role of patient. However, a long-standing history of chronic paranoid schizophrenia offered some explanation and indicated severely compromised agency to act on his own behalf.

LOCAL TITLE: Discharge Summary

STANDARD TITLE: DISCHARGE SUMMARY APR 01, 2003@14:44

C22 has been very delusional and paranoid for the past two weeks prior to his admission. Initially he reported sleeping well with a good appetite. He does smoke cigarettes excessively. Apparently he has been very compliant with medication intake. During his evaluation in the Emergency Room, C22 reported that a snake had bitten his thigh and he began removing his trousers to show the scar. He was able to be redirected at that time. Patient has no suicidal or homicidal ideation. He does report that he wanted to leave the hospital and reported that he was not sick and that he hates the VA Medical Center.

And finally for C26, the case we have been following through the stages of GTM analysis, as his dementia progressed continued to resist the role of patient.

LOCAL TITLE: PSYCHIATRY CONSULT

STANDARD TITLE: PSYCHIATRY CONSULT

DATE OF NOTE: JAN 07, 2008@09:13

Per record, C26 has history of delusional thinking. On the ward C26 also consistently refused his medications, and had suspicion of the treatment team's motivations. His team there was often accused of using "hypnosis" on him and thought the team was "a bunch of witch doctors." C26 was not admitted on any psychotropic medications on the ward, and refused his meds, labs, imaging as well as refused any offers of psychotropic

medications. During his time on the ward C26 was felt to lack capacity. A consult was placed with the ethics committee, and a forced medical treatment order was obtained on 11/21/07. At that time, patient consistently refused all medications and treatment except that forced by order. C26 was not reported to be combative with staff physically or verbally in his refusal.

As documented, the lack of commitment to the role of patient indicated weak or non-existent patient role salience and made caregiving difficult during the veteran's time at the VAMC; and, of course, impossible when they eloped or left against medical advice (AMA). Considering that the patient role may have demanded a passive or depersonalized stance, devoid of agency at times, it was understandable that veterans might seek to make rather than simply comply and play the role as expected.

Emergence of agency as the core category. As the literature review and analysis continued, the seemingly contradictory nature of the term *Shared Autonomy* led to the emergence of agency as the core category. Readings on psychological issues of agency (Martin, Sugarman, & Thompson, 2003), and the significance of self efficacy (Bandura, 2001), combined with reflection on the relational processes shown in Figure 1, demonstrated that clarification of agency encompassed documented veteran-formal caregiver and formal caregivers interactions.

Veteran's capacity, care desired, lifestyle, and percentage of service-connected care categories could all be seen through the lens of agency. Mental and physical capacity was in one sense a measure of agency. A veteran with some degree of capacity had a related degree of agency. The actualization of care wishes was dependent on the exercise of agency and agentic action. Lifestyle choices could represent functional or dysfunctional agency and over time could enhance or limit lifestyle options. The percentage of service connected coverage strengthened veteran's agency by providing fiscal resources to pay for care services.

The formal caregiver factor of formal relations, both among formal caregivers and between formal caregivers and veterans, could be seen as, and in the data was often about, identifying who would decide what on the veteran's behalf. Whether veterans' relationships with formal caregiving agents were conflicted or collaborative they were, in this study, necessary.

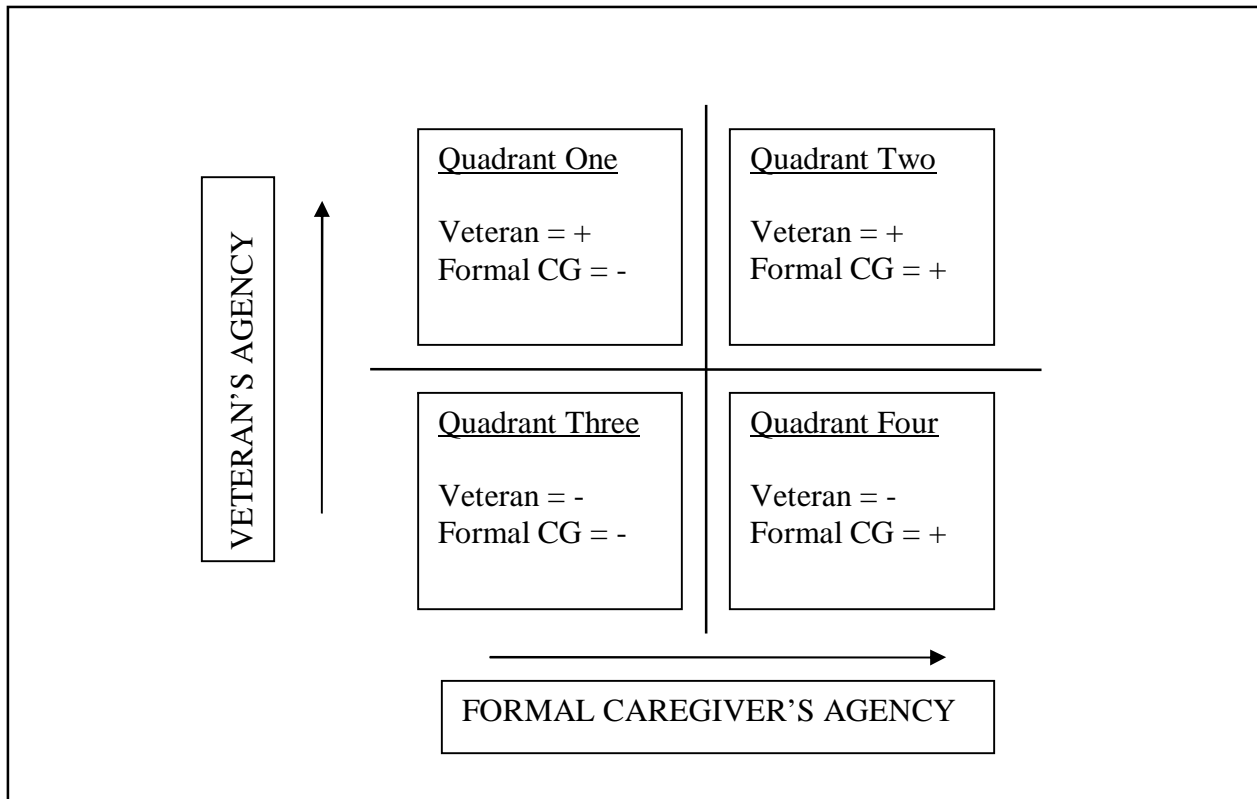
In practical terms, when we want help with taxes we go to an enrolled tax agent, when buying a house to a real estate agent, and when we are not sure, or incapable of deciding, what to do in a healthcare crisis most would prefer a healthcare professional as our agent. Acting for the

veteran is another definition of agency, with the caveat that the veteran should act as their own agent to the degree possible, rather than deferring to paternalistic agentic action taken by professional caregivers.

Further, interactive factors dealing with End-of-Life (EOL) issues, patient role salience, and ethics questions of coercion or deception all related to clarifying agency. It was important to identify who would decide if and when caregiving should shift from attempts to cure to providing comfort care and pain management. Patient role salience impacted the salience of surrounding caregiver's roles and there was no implied or stated role more important than effective agent acting on behalf of a veteran in need. And, questions of coercion and deception could be framed in agentic terms. There were times when the police were called to limit a veteran's agency when he may have become a danger to himself or others. And what might be considered deceptive in normal circumstances may be ethical and considerate with a seriously demented patient. If such a veteran believes he has been bitten in the groin by a snake the doctor or nurse who can validate and reassure the patient that the wound is not serious has not acted unethically, nor shunned their responsibility as the veteran's healthcare agent.

Figure 2 presents an agency grid. In quadrant one the veteran has agency and the formal caregiver does not; quadrant four reverses that polarity with formal caregivers having agency. Quadrant Two is the case where both veterans and formal caregivers possess agency; probably the desirable condition if relational ethics are in play. And, quadrant three shows neither the veteran nor formal caregivers having agency.

Figure 2. Agency Grid



Case analyses demonstrating Figure 1 and Figure 2 processes. The following sampling of case analyses demonstrated the specifics of case exploration that led to understanding relational processes described in Figure 1 and agency tradeoff shown in Figure 2. Coded quotations meaningful to the four stages of analysis supported substantive theory development, including quotations selectively coded to refine agency theory, were presented.

Referring to Figure 2, and back to Figure 1, the vertical and horizontal communication channel documentation recorded continuing negotiation of agency. Case circumstances were dynamic and could change quickly as with C15 (Living Will) or more gradually as with veteran C18 (Only Pain). Both of these cases began in quadrant two and shifted to quadrant four; C26 (Refused Care) followed the same trajectory. C10 (Risk and Danger) followed a different course, from being emotionally out of control at time of admission to the VAMC (quadrant four), going through homicidal and suicidal ideation, to medication management, ongoing monitoring, and discharge back into the community (quadrant two).

C4 (Thirsty AMA) was an interesting case where relationship with VAMC staff was more conflicted; the case circumstance seemed to move between quadrants one and four. At the VAMC C4 was restricted to the ward and when he left care against medical advice (AMA) he moved to quadrant one until his next admission to the VAMC. C16 (Different Opinions) also left care AMA and got into trouble with the health department and developed gangrene while exercising his agency in quadrant one.

Coded quotation examples for C6 (Motorcycles and Narcotics) and C10 (Risk and Danger) led towards determining dimensions of the Veteran's Lifestyle and Ethics categories:

LOCAL TITLE: PCT P

STANDARD TITLE: PRIMARY CARE NOTE

DATE OF NOTE: MAR 30, 2005@16:55

I did meet with C6 today to discuss his pain management issues. This is my first meeting with C6. Issue discussed was his disagreement with the narcotic contract and his right to future pain management. We had a long discussion, I listened to C6's concerns and discussed each one individually and explained to him the rationale behind those statements and what they really mean. I gave him some clinical scenarios that happened to get him to understand the reasoning behind this narcotic contract. He had objections on some of the wording of the contract and he made some handwritten changes to the contract, I made a copy for him to take. I advised him that I will turn this over to the administration at the VA (contract is not signed by either one of us). He offered me a copy of a narcotic contract that he researched from the academy of pain management. I shared with him that this is not something that I will be willing to accept as a physician. It was a long discussion, tried to be understanding to his concerns, reassured that this is not to violate his rights and tried to get him to see the bigger picture.

Signed, MD, Staff Physician

The entry above was coded as doctor-veteran relationship, lifestyle issues, and substance abuse. After having a serious motorcycle accident, as explained in documentation from five years earlier, C6 wanted to have narcotics and would not agree with the contract requirements for regular urinalysis to monitor his use of powerful narcotics.

LOCAL TITLE: COMPENSATION & PENSION EXAM

DATE OF NOTE: MAY 10, 2000@10:00

PRIORITY OF EXAM: Review. The veteran presently has a 90% service-connected disability for a hip prosthesis. C6 is a 37-year-old white male who was last seen by this examiner on September 10, 1998 for the same problem. Before that, he was seen by Dr. Cxxx on February 24, 1997. The veteran was in a motorcycle accident in 1984. He was hospitalized at the Naval Regional Medical Center for five days and then he was medically evacuated to General Hospital in XXX.

Since C6 had a motorcycle accident while on active duty his serious injuries were rated at 90 percent in 2000 and by 2005 were rated at 100 percent service connected (100%SC). After the meeting with the staff physician in March of 2005 the veteran wrote a letter to the VA National Ethics office. There were seven documented phone conversations between VAMC staff and the veteran during 2006 and into 2007. The last contact with the VA was in July of 2007. There has been no contact with the veteran since that time. Coding of this passage noted conflicted formal relations between the VAMC physician and the veteran and questions related to lifestyle and the desire to have access to narcotics without accountability. Communication reached an impasse with physicians acting as agents of the VAMC and the veteran as an agent on his own behalf. Although the veteran was able to get a lot of attention from the VAMC staff, he was unable to reach his goal of narcotic pain management without accountability and severed his relationship with the VA Medical Care system. No subsequent CPRS data appeared after the last phone contacts in 2007.

Agency risks and dangers, C10 analysis. C10 (Risk and Danger) was a troubling case that coded for frightening lifestyle and behavioral issues and later selectively coded for issues of ethics and appropriate limitation of agency through legal commitment to treatment. Segments of documented C10 case history are followed by a violent episode, elopement, and finally recommitment by a judge. This case was a glaring example of the need to question when and where veteran agency should be assigned and validated. The outcome, through ethical coercion and medical commitment, was to control behavior with psychoactive medication and sexual control through chemical castration. Regrettably, after many months of research it was determined there were no treatment facilities to help this veteran, except in the prison system, and he was not willing to turn himself in and confess to legal authorities. C10's case had a total of 43 quotations coded for REL:FORML:DOC-VET; five coded quotations from an extensive Discharge Summary document dated 08/05/2006 follows.

The following day during morning rounds, C10 began to divulge more about his life; both his internal world, experiences as a child, and as an adult. His early life history was remarkable for frequent moves, both parents being alcoholic, mother abandoning the children when he was approximately 11, and his going to live with a maternal aunt, and his father so impaired by alcoholism that he could not care for the children. He also informed us that he had been molested as a child by his elder siblings. He was one of eight, and the third youngest. He stated that he enjoyed it and that he then began molesting his two younger sisters, whom he raped repeatedly over many years. He stated that he began raping them when he was between 10 and 12 years of age, and at times, he stated he could be quite brutal with them. He also stated he had tortured animals; that there had been a dog that he took pleasure with pushing its head under the water and almost drowning it, that he had pulled a cat's leg out of its socket and intimated that he had poured acid into the cat's eyes. The cat mysteriously died, he said, several months after these incidences. He showed little remorse.

In an earlier document C10 was described as a Vietnam War Medic. Later, the same report documented military history, disturbing violence, and homicidal ideation:

MILITARY EXPERIENCE: C10 served in Vietnam in the army as a medic. His job was to dispense medications, such as anti-malarial medications. He was reprimanded twice; reasons being, that he did not dispense the medications to the troops, but only to the officers. He did not know why he had done this. C10 stated that when he engaged in acts of aggression, such as torturing the animals, beating his infant daughter's face, taking the broomstick to his 7-year-old stepdaughter, that these were very arousing for him sexually. He also stated that on the day just prior to being admitted to VAMC, that he had been mocked by some boys in the park across the street from his home and that he had a very strong impulse to severely injure one or all of them. He did push one to the ground. He stated that he truly was homicidal on the day or two prior to being admitted.

Later in the document there was an explanation of the veteran being sent to an external sexual assessment center for extensive sexual arousal testing and evaluation.

This evaluation consisted of two different days of going to the center. On the first day, it was to write down his history of deviancy and to provide his life history. He was scheduled to return the following week, and while en route to the center in Rxxxx, he

eloped. The undersigned physician, while being part of a group of law enforcement agents from throughout the city of Rxxxx and Sxxxx, and the VA Police, did an extensive search of Rxxxx and Sxxxx, all airports, car rental, bus stations, and shelters were notified of this man and his potential for dangerousness, and that he was at large. Fortunately, while driving on Sxxx Boulevard, the undersigned looked out the window and saw C10. She informed the police officer, and he was apprehended and brought back to the unit without incident.

When he was brought back to the VAMC, he was extremely distraught. He was placed on a one-to-one and remained in the most restricted part of the unit. Within several weeks, and with much security, he returned to the Sexual Assessment Center, where he completed his testing. Again, the results revealed that he preyed upon 5-to-10-year-old Caucasian females, and occasionally, 5-to-10-year-old Caucasian males. Of note, is that he did try to rape a neighborhood boy when he was 10 years old. The boy got away, and C10 reports being enraged that he did not get what he wanted. He expressed no recollection of fear or regret or shame.

Later the discharge document recorded the lack of available treatment and the VAMC's accepting the ethical responsibility of keeping this veteran in treatment until it was appropriate to discharge him.

Later C10 was deemed well enough to be transferred to the open side of the ward. The team made exhaustive attempts to find treatment programs for the patient. We were unsuccessful for two reasons. One, most programs are for sexual offenders who have been charged and convicted and there is treatment in facilities for these criminals, or two, those treatment programs where an individual is eligible even if he has not been convicted would take only younger, usually men, and those that were deemed healthier than C10. C10 met the criteria for severe-to-catastrophic pedophilia and sexual sadism. There was no outpatient program that felt it was at all safe or appropriate to accept him, and again, no residential treatment programs would take him.

On March 18, 2006, his commitment ran out and it was the team's decision after consultation with Dr. Sxxx, Dr. Cxxx, and after several ethics consults in which this case was discussed, deemed that continued hospitalization was necessary because of the potential for dangerousness to others. The patient hired his own attorney, and the

recommitment proceeding took between two and three hours. The judge determined that the patient should be recommitted.

The following discharge note and follow up progress note indicate the case outcome for C10 of stabilization and discharge on 7/20/06. C10 entered the VAMC on 9/20/05. C10's case covered ten months of hospitalization, plus follow up.

Following recommitment, the team had, as we had before, approached the patient about the possibility of being treated with chemical castration. C10 had refused this and many studies had indicated that for individuals who are motivated for such treatment, chemical castration can be very effective. He and his wife were given literature. We talked to him about the possibility of leading a life where he was free of fantasies and sexual urges all the time. We talked to him about dealing with impotency which would result from this treatment. Eventually, he and his wife opted for the chemical castration. The agent used was goserelin. Initially, C10 was given it monthly. Following an initial rise in testosterone, which is expected when this drug is first used, and the patient reported marked increase in urges and fantasies, the testosterone quickly fell. With that fall, came a decrease in the frequency and intensity in his fantasies and urges. C10 was not informed that the testosterone would rise post first injection. We did this so that we could see the genuineness of his statements regarding urges and fantasies. Full effect and benefit of these injections is not expected until after the second or third injection.

Mr. C10 was asked on a daily basis to score his fantasies and urges using a scale of 1 to 10, 10 being the most intense urges, and 1 being the least urges, or no urges. Following the two and one-half to three month mark from the first injection, he consistently reported Monday through Friday that urges and fantasies both were between a 2 and a 3, just about every day. On the weekends, they generally were a 5/5. We discussed this and the implication it had for the importance of keeping busy, as distractions and other activities would prevent him from being preoccupied with sexual fantasies and urges. The homicidal urges subsided as well, and fantasies.

We felt that Mr. C10 was being candid with us, as he did not conceal that his urges were significantly more increased during periods of more idle time. His testosterone level fell to 2 or 3, by the end of his hospitalization. Preparations for his discharge were intense, as we realized, as did he and his wife, that he would need many modalities of treatment and

support to help him function on the outside and remain healthy and not a danger to others. We also talked about how long this hospitalization had turned out to be, and difficult at times, although, ultimately helpful, but at a tremendous cost. We all agreed and understood. We asked if this would prevent him from seeking help in the future. He stated that it would not, that he detested leading his life consumed by fantasies and stated that when he had entered the hospital, his urges and fantasies were a 10/10 all the time. The different individuals and groups involved in his aftercare are the following; psychiatrist at Hxxx, the Urology Department at Hxxx, where he will continue to get the Goserelin injections, the MICHM Team, most likely. They were somewhat ambivalent, although, on the day of this dictation, the undersigned had phone contact with the patient and his wife and they reported that Mxxx had come to the house. The patient also is very involved with the Jehovah's Witnesses, who know of his problem, and they agreed to provide much supervision and support. They also stated they would continue as they had, ever since learning of his problem, to prevent him from having any possibility of interacting with children. Mr. and Mrs C10 agreed he would continue receiving Goserelin treatments. On July 6, 2006, following a meeting in which Dr. Cxxx, Dr. Dxxx, Mr. and Mrs. C10, and Lxxx were present, and there was a phone call with the MICHM Team in Hxxx to discuss the aftercare. It was deemed that Mr. C10 was well enough to be discharged from the hospital with the supports in place.

DISCHARGE MEDICATIONS:

(Researcher removed a list of nine additional medications)

10) Goserelin 10.8 mg implant every three months, next injection August 11, 2006.

ADDITIONAL DISCHARGE RECOMMENDATIONS: Recommendations are that the patient is to never be left alone with children, that he should be closely monitored if he were in the presence of any children, that the patient would continue to seek support and structure from his church.

Signed, M.D., Psychiatry Attending

And, finally, the follow-up progress note:

LOCAL TITLE: ATTENDING NOTE

DATE OF NOTE: JUL 20, 2006@15:06

Phone contact with Mr. and Mrs. C10. Both report that they are doing well, that the transition from hospital to life in the community has been stressful but feels more and more comfortable daily. He is hardly tearful at all now. The former pt stated he had spent the morning with his Jehovah Witness brothers and it had been good. Ms. Jxxx had come to the house to talk about and organize his medications.

Signed, M.D., Psychiatry Attending; Signed: 07/20/2006 15:12

This case was given extra analytical attention for several reasons. C10's case was the most severe and challenging ethical dilemma in the population; it exemplified the VAMC's commitment to meeting its ethical responsibilities; and, it showed that even the most difficult case can reach a resolution with the coordinated efforts of the VAMC team and the larger community. The willingness to proactively limit the veteran's agency and to act as the veteran's agent and caregiver through his process of anger, psychosis, deadly threats to staff and peers, denial, depression, suicidal ideation and intention requiring physical restraints, to dilemma resolution, was potentially a study in itself.

In terms of relational ethics, C10's case included both coercion and deception deemed appropriate given larger ethical concerns. The balance of give and take in this case meant VAMC formal caregivers met their obligations to both the veteran and the larger community; while the veteran, with coercion, weathered the role of patient and eventually gave up all sexual desire through chemical castration. The relational-ethical space between caregiver and patient went through powerful dynamic changes as the veteran's mental and emotional challenges were incrementally met. At first the space was frightening and threatening on both sides. Later, a controlled and accountable discharge plan changed that space to discharge status and least restrictive level of adequate care and follow up.

Changing capacity and agency, analysis of C15 and C18. Later selective coding of study one cases for agency, in order to integrate and refine substantive theory, produced 323 coded quotations; samples from several cases follow.

Documentation for C15 presented a sudden and dramatic change in veteran's medical condition, and thereby agency, and produced an End-of-Life (EOL) situation.

LOCAL TITLE: NEUROLOGY CONSULT DATE OF NOTE: APR 29, 2005@12:03
Neurology was requested to give another opinion regarding prognosis following recent cerebral hypoxic event (*brain starved of oxygen*). Briefly, C15 had cerebral anoxia (lack

of oxygen to brain) following cardiac arrest on 4/25/05 requiring prolonged resuscitation efforts (*details per CPRS*). Repeated neuro exams since then have only shown minimal brainstem reflexes. EEG is almost flat. Neuro: Unresponsive to call, tactile or painful stimuli. No spontaneous eye opening. Mild roving eye movements in all directions spontaneously. No response to visual threat. Pupils 2-3mm reactive to light. Corneal reflexes + b/l. Some gag spontaneously and to stimulation. No extremity movement even to deep painful stimulation.

C15 had passed away by the time of the following discharge summary.

LOCAL TITLE: Discharge Summary

STANDARD TITLE: DISCHARGE SUMMARY DATE: (*Deleted for Confidentiality*)

C15, a 76 year old man was admitted s/p (status post, an event happened) code in pre-op room just at time of iv (intravenous tube) placement. He was to have laser surgery on prostate on day of admission; s/p code and intubation he remained comatose with no signs of recovery. After neurology review, it was decided by family to remove vent support on 4/30. IV fluids via previously placed femoral line, O2 n/c and foley catheter remained. Over following 11 days had periods of tachycardia, fever, hypotension, and beginnings of skin breakdown despite routine care. No recovery was noted. Skin became mottled and cyanotic with increased breakdown and melanotic stools were noted. He was in no apparent pain or uncontrolled distress prior to his death on (*Date removed*) at 0205 am. Given the unexpected circumstances of this admission, an autopsy was offered, and the medical power of attorney did want this.

C15's case showed, most dramatically, how suddenly a veteran's physical and mental capacity can change. VAMC staff in the operating room were preparing for a routine prostate procedure when a traumatic medical event occurred. Whatever agency the veteran had when he gave presumed consent to have the prostate operation performed was instantly transferred to a medical team making unsuccessful efforts to revive him.

C18's case was one of gradual loss of mental capacity and agency. The following data entry was over ten months prior to his Ethics Committee Referral Date (ECRD) of March 24, 2005.

LOCAL TITLE: SPEECH PATHOLOGY CONSULT REPORT

DATE OF NOTE: MAY 21, 2004@14:35

C18 was admitted to VAMC 5-20-04. Patient is a 74 y/o male resident of VVCC admitted with CVA. PMH: OBS, h/o ETOH abuse, COPD, malnutrition, h/o (*history of*) pulmonary TB. He is cachectic. Nursing at VVCC states he is afraid but a very sweet person. They report he was on a mech soft diet previously. He states he continues to "smoke but less than 1 ppd (*pack of cigarettes per day*)." C18 incorrectly stated his diet at VVCC, therefore personal information he gives may or may not be correct. C18 was not oriented to place or month. Consult request received to eval and treat for speech and swallowing. Patient c/o (*complained of*) needing to urinate and the urinal was brought, however, pt. was unable to go. SLP had staff reposition pt. for swallowing trials and he was curled up with his head on the rail.

Signed, Speech Language Pathologist; Signed: 05/21/2004

By March of 2005, just prior to the ethics consult for his case (see Table 12, Chapter 3), this veteran's health status had deteriorated enough to result in a request for both an ethics committee and a palliative care consult, indicating a dire prognosis.

C18 is a 75 year old male admitted with hemoptysis (*spitting up blood*), later developed respiratory failure and was intubated, now 3 weeks post intubation and now with tracheotomy; C18 has not shown signs of recovery. He has hx (*history*) of advanced dementia and sp (*status post, event occurred*) CVA (*cerebrovascular accident*): with left sided weakness. There is a left upper lobe lesion that appears to be aspergilloma (*clump of fungus*) but not confirmed. We request palliative care consult as well as ethic consult.

Signed, MD, Staff Physician; Signed: 03/25/2005 22:07

The combination of advanced dementia and brain stroke left C18 with little or no capacity and in the hands of VAMC caregivers acting as agents on his behalf. The request for a palliative care consult meant that cure appeared unlikely, only comfort care may be provided, and that the veteran was estimated to have less than six months to live.

Implications of the Agent-Principal Relationship

Theory development in study one provided an important implication for relational ethics that aligned agentic caregiving with veteran care preferences. Agent-principal relationships, at the core of this substantive theory, implied correspondence between veterans care preferences and values and the actions of formal caregiving agents acting on the veteran's behalf. Effective and ethical agency would exemplify relational ethics as defined in Chapter 1 (Introduction, page

2, and Table 1, pages 14-16). The actions of an ethical agent should be guided by and congruous with veteran's care preferences whenever possible (Dossetor & Bergum, 2005). That quest for agreement with veteran's wishes was apparent in the data, as recorded by a social worker for C4 (Thirsty AMA).

Assisted Vet in going off-ward. Vet enjoyed his time off-ward and bought a coke and a Danish pastry. C4 was appropriate and expressed his hopefulness in getting discharged from the VAMC as a result of the Ethics meeting. This social worker discussed the possible outcomes, and the importance of Vet remaining patient in the meantime (particularly with staff). Undersigned will continue to support Vet and provide ongoing case management while he is at the VAMC.

And, another social worker note for C16 (Different Opinions),

Met with ethics committee this morning, decision was made after MD spoke with Dr. Sxxx who stated that C16 can go home if he agrees with home health services and if an APS (?) referral is made. Spoke with veteran who agreed with HH (*Home Health*) services and requested assistance with a ride home today. Veteran has his scooter here so this writer contacted Bxxx in travel who indicated that he could take veteran home after 2pm today. Placed travel request and he will be taken home today via VAMC TRAVEL.

And, C19 (Comfort Only) presented a case where the veteran was in and out of the VAMC eleven times in the course of three years since he preferred assisted living. He was allowed to live in the least restrictive level of care and when he became emotionally unstable the VAMC would admit him, get him stabilized, and discharge him back to assisted living.

LOCAL TITLE: Discharge Summary

DATE: MAY 13, 2004@11:38

This is C19's 11th admission here in the past three years. He lives in an adult home and had gotten along very well except for these occasional bouts of grandiosity psychosis where it makes his care uncontrollable. He is usually quite demanding during this time and no one can be at peace with him because of his insisting that they listen to his ideas and other psychotic behavior. He also has other physical problems.

C19 was in good psychiatric condition compared when seen here on his two previous hospitalizations where he was overtly psychotic with delusions and hallucinations.

Later the veteran wanted to stay at the VAMC but was convinced to return to an adult care facility. This may be a case where larger ethical concerns about available bed space for other veterans or limited resource issues at the VAMC may have had an impact.

HOSPITAL COURSE: Quite uneventful once the medications were discontinued. C19's blood pressure remained within normal limits. He was feeling more comfortable, but continued to complain of his sore knee where he had fallen before he got here. It was tender to touch, but there was no alteration in the movement of the joint and he was walking, using the wheelchair for stabilization. C19 got along very well and reluctant to go back to the Adult Care Home, but was willing to do so when confronted with the fact that he had reached his maximum potential and was much better than he had been on his two last discharges.

Agent-principal relationships explored in study one typically sought agreement with veteran's care wishes. Again, this property of agency was dimensional, varying from conflicted in C10 to mostly harmonious in C19. The argument for alignment of agency with veteran's care wishes was not specifically coded for but was abstracted from coding and categories grounded in the data and later selective coding related to agency.

The alignment and alliance of formal caregiver and veteran agency may have been impacted by conflicting role commitments, as well as changing role salience and salience hierarchies. Case documentation clearly and appropriately reflected the perspectives of professional caregivers employed by the Department of Veterans Affairs. Doctors, nurses, social workers and other VAMC professionals were clearly committed to their disciplinary roles, and in that sense, acted as agents of their respective professions.

These professionals were also VAMC employees and members of the largest health care system in the country. Thereby they were also agents for the VA, providing care in an environment of increasing need and fixed resources to meet those needs. It was not possible to determine from the data in this research the salience hierarchy (see Table 3, Chapter 2, page 26) of these varied roles.

Concluding Remarks

As presented in the prior cases, there were notable examples of both conflict and concordance between roles of professional, employee, and care giver. C6 attempted to convince a doctor to give him drugs without monitoring. C16 decided he did not want to remain a patient

and left care against medical advice. Role making was also apparent in C26 where a VAMC attending physician's identity standard as a healer, when faced with a request to terminate life-sustaining treatment, may have motivated role salience as a doctor and healer to sustain care, dependent on congruence between personal beliefs, VAMC policies and procedures, and professional standards as a doctor. However, there was an underlying sense conveyed in the documentation, especially in Advance Directives, to align professional caregiver's agency with the veteran's desired care. The agent-principal concept anticipated the emergence of congruence as crucial to substantive theory development in Act II, study two.

In study one, SSSI conceptions (see Table 3, Chapter 2, page 26) of veterans and formal caregivers acting in the social structural context of the VAMC combined with the core category of agency. Analysis of these cases led from coding interactions, to creating categories, and through constant comparison of large volumes of data to focus on veteran and formal caregiver's agency. Case documentation came to be understood as reporting how agency was assigned, negotiated, and played out in these caregiving dramas. Despite all the levels of case complexity, GTM led to a parsimonious descriptive substantive theory for study one, the **dynamic process of clarifying agency**.

This chapter concludes by viewing several cases through the substantive theoretical lens and referring to relational processes in Figure 1 and the agency tradeoff grid in Figure 2. In C13 (Stop Treatment), nursing staff reported having meaningful conversations with C13 in mid-summer. Within a couple of weeks C13 "seemed more tired" and "wouldn't talk to you most of the time, he just stared." Nursing staff observed there were times when he seems more lucid, energetic, and engaged, suggesting a waxing and waning of well being. Documentation shifted back and forth between horizontal and vertical channels of communication. However, C13's mental status declined after insertion of his PEG (*feeding*) tube. He began showing signs of depression and asked that his dialysis treatment be stopped. One morning a couple of weeks later, just after lunch, this Air Force Vietnam era veteran passed away.

Early in his stay at the VAMC C13 and his caregivers were exercising agency and functioning in quadrant two with both communication channels functioning pretty well. As C13's physical health declined he became depressed and tired of treatment. The case moved towards quadrant four as agency shifted from C13 to his formal caregivers, vertical communication predominated. Although the ethics committee made recommendations

considering family and spiritual issues, influencing communication in both channels, care protocols remained those proposed by VAMC staff until C13, a Vietnam era veteran, died.

C17 (Internal Solution) was functioning well (quadrant two) in mid-winter after being admitted to the VAMC for bowel problems that were successfully treated and he was discharged home (quadrant one); communication was operating in both channels up to discharge. By late winter he had been readmitted for more serious bowel problems requiring surgery that led to life threatening complications in the operating room (quadrant four). C17, subsequent to suffering from life threatening health complications, and without an advanced directive or living will, was barely existing (quadrant four) for a few weeks. As the veteran's devastated capacity mediated communication in the horizontal channel the vertical channel drove the documentation. Near the end of winter, this Air Force Vietnam era veteran passed away at 5:20 in the evening.

C6 (Motorcycles and Narcotics) discussed previously offered an example of a case that culminated in quadrant three where neither the veteran nor formal caregivers possessed agency (quadrant three) to deal with the health issue at hand, pain management. Although the case began with both veteran and formal caregivers having agency (quadrant two) up until October of 2006, the case later became conflicted, with both parties eventually losing agency (quadrant three). Veteran's inability to understand or accept the necessity of a narcotics contract and lack of mediation agency eventually ended communication in the horizontal channel.

In February of 2005 a letter was sent to C6 after several telephone conversations with VAMC doctors. It stated, "In regards to your request for the morphine to be restarted, you will need to come by the office, sign the updated version of the narcotics agreement, you will also need to have a urine drug screen and random testing." The veteran refused to accept these conditions.

The last correspondence was sent to C6 in July of 2007. It reiterated, "In reply to your recent call for morphine, I am attaching a copy of the letter that I sent back in February. Since you did not respond, and have not been seen in the clinic since Oct 2006, I am informing you that I will not be able to provide you with your request."

This final case provided the only example in study one of failure of dynamic relational ethics and agency clarification processes. This failure to establish agency and to keep the horizontal communication channel open had implications for relational ethics. The inability to find common ground, to find a compromise in aligning agentic caregiving with patient care

preferences, led to the veteran severing all contact with the VAMC. He may have found dysfunctional ways to medicate his pain; he may have become another homeless veteran, he may be doing fine; or he may be dead.

The curtain has closed on Act I. We observed several dramatic scenes from our 13 productions. We saw that our main characters often needed agents to act on their behalf. Figuring out who should have the authority and responsibility to act when was daunting. Further, scenes and circumstances changed quickly as clarification of agency attempted to keep pace; onward to Act II and barbarians waiting at the gate.

CHAPTER 5 – STUDY 2 – Formal-Informal Caregiver Relations

Main study two focused on case documentation describing interactions between VAMC staff and veterans' significant others. It explored ethics committee member and medical center staff communications with veterans' informal caregivers, family, and friends regarding veterans' health problems. Investigation of formal-informal caregiver relations discovered psychosocial and ethical issues not apparent in study one. These documented interactions confirmed the impact of relational ethics processes, as understood from the varied perspectives of ethics committee members, medical center staff, and veteran's significant others, on attempts to reach agreement on recommendations and decisions to resolve ethical dilemmas.

The main question posed by research in both study one and study two was, how does case documentation and documented processes of resolving ethical dilemmas in institutional healthcare for veterans reflect relational ethics? Relational ethics, defined in chapter one on pages two and three, was reviewed in more depth in the literature, in parallel with the study two research process.

From our theatrical metaphor perspective, and at least at times, as seen by VAMC staff, the barbarians were kept at the gate in study one. In Act II study two they were on stage and very much a part of the play. Actors playing the parts of professional nurse, doctor, and social worker were forgiven for seeing the new players as sometimes too emotional and unpredictable, crowding the stage, and further complicating an already complex production. Family-member and significant-other players came with all the best intentions, new scripts, and agendas exclaiming what the main character really needed. The larger Act II cast played their respective roles and portrayed the tension created as different actors advocated for what they saw as appropriate care for the veteran.

As in study one, the focus was on ethical concerns relevant to resolving veterans' healthcare crises and the unit of analysis remained caregiving relationships. The research was again guided by a social structural symbolic interaction (SSSI) theoretical framework, including aspects of roles designated and reinforced by the social structure of the Veterans Affairs Medical Center (VAMC).

Four-stage grounded theory methodology (GTM, see Table 6 in Chapter 3, page 38) applied in study two contributed to scholarship in relational ethics and autonomy. The relevant

literature review is followed by data analysis and substantive theory development. References to veterans use only case numbers (e.g. C8, C11, C23, etc.) to maintain confidentiality.

GTM analysis discovered the initial pivotal concept of agenda, to determine, respect, and advocate for veteran care recipients' autonomy. The ethical agenda was to determine and promote things to be done or considered in providing care desired by autonomous veterans. Stage three analysis moved beyond understanding autonomy as individualistic self-governance free of personal limitations and outside interference. Relational ethics that considered veterans' autonomy in social structural and interpersonal context posed advocacy for the core category of relational autonomy that validated other ethical concerns, and resource demands, and included obligations as well as rights and entitlements. Substantive theory developed in stage four of study two was the **agenda to advocate for relational autonomy**.

Study two explored indicators within the archived data of relational ethics (Bergum & Dossetor, 2005; Boszormenyi-Nagy & Krasner, 1986; Hargrave & Pfitzer, 2003; Van Heusden & Van Den Eerenbeemt, 1987) at work, along with signs of entitlement, obligation (O'Neill, 2002), and attempts to balance give and take in caregiving relationships. Relationships between formal and informal caregivers focused on upholding varied understanding of what was appropriate, principled (O'Neill, 2002), relational (MacKenzie & Stoljar), veteran autonomy.

Study Two Literature Review

Although grounded theory methodology emphasized an inductive approach to substantive theory development it did not preclude deductive input to enrich qualitative research perspectives (Daly, 2007). Therefore, this literature review includes virtue and care-based ethics (Day, 2007) and relational ethics concepts developed by Ivan Boszormenyi-Nagy, or Nagy, (1986) and forwarded by O'Neill (2002). In healthcare, relational ethics was also conceived as a *third entity* between interacting persons, a *relational or ethical* space, that required attention and nurturance (Bergum & Dossetor, 2005) through mutually respectful engagement, freedom of choice, acknowledgement of uncertainty and possibility, and a supportive environment.

Relational autonomy was defined in caregiving as interpersonal (MacKenzie & Stoljar, 2000) and placed veteran patients' autonomy in social context that validated other ethical concerns and resource demands. Many veterans, particularly in study two, had significant others very engaged in the caregiving and care decision making process. Veteran's autonomy was circumscribed, for better or worse, by a web of relationships with others. Veteran's care was

subject to financial constraints, as veterans from current wars placed additional demands on limited resources.

Relational autonomy was also conceived as principled autonomy (O'Neill, 2002) that linked obligations to rights. Veterans, who refused to change destructive lifestyle habits, and still felt entitled to limitless care, potentially ignored the needs of other veterans in need of care resources. The desired outcome, in both relational and principled conceptualizations, was to build trust and trustworthiness (Boszormenyi-Nagy & Krasner, 1986; Hargrave & Pfitzer, 2003; O'Neill, 2002); trust that veterans would be provided with quality care that honored their values and care preferences, without ignoring the reality of limited care resources, and the impact of care decisions on larger relational and ethical issues.

Nurses, as frontline caregivers, often interact with family members and significant others. In the caregiving context, Day (2007) promotes virtue and care-based ethics as an alternative to Kantian utilitarian theories. Day's clinical ethics offers a view of ethics and virtue congruent with changes in modern society. Virtues, seen as socially embedded rather than individual in nature, develop in the context of practice. Caregiving, especially nursing care, has a long social history delivering inherent *goods* of health and well-being. Delivery of these inherent *goods* is experienced in caregiving context. Such *goods* are understood in terms of the practice and recognized while engaged in caregiving practice i.e., while having the associated experiences. Doing the right thing in healthcare is always embedded in context. Day goes on to differentiate between virtue, care-based ethics and Kantian utilitarianism. She poses that utilitarian philosophers ask, "What should I do?" Whereas virtue and care-based ethics asks, "What kind of nurse, should I be?" She also points out that rights and individualistic notions of autonomy are not sufficient to sustain empathetic care practices.

Communication skills and relational work, though often unacknowledged, were at the heart of doing the right thing in a specific care circumstance (Day, 2007). Such relational work, when present, promoted healthy interaction between informal and formal caregivers, leading to ethical relationships, in resolving caregiving dilemmas faced by veteran patients.

Relational ethics literature review. Caregiver-care recipient relational support processes and ethical concerns can be conceptually framed around the four dimensions of Nagy's contextual marriage and family therapy (Boszormenyi-Nagy & Krasner, 1986; Boszormenyi-Nagy & Spark, 1973). The *factual dimension* includes veteran's heredity, genetic roots, physical

condition, and personal history. The *psychological dimension* involves internalized motivations, felt needs, personality, and mental health issues. The *transactional dimension* encompasses observable patterns of interaction with others and emphasizes interpersonal systems and subsystems, in this case, between formal and informal caregivers. In the VAMC veteran's caregiving context, Nagy's *transactional* and *relational ethics dimensions* are most germane. These two dimensions are complementary and, as with all four dimensions, have significant conceptual overlap.

The transactional dimension can be used to frame relationships between formal VAMC and informal family caregivers. This dimension focuses on observable communication patterns between people; including aspects of system and subsystem functioning, social structures, and role definitions. Contextual fields of service, including caregiving, sustain meaningful human relationships and thereby relational support for caregivers and care recipients. Perceptions of adequate social support and connection are significantly related to positive attributions of quality of life and a sense of well being (George, 2006). Without perceived support, effective reciprocal caregiving relationships cannot be sustained long term. Although relational support is not generally the primary intent of service delivery, quality of personal relationships, no matter the context, significantly impact quality of life for both care givers and recipients (McIntyre, 2003).

The transactional nature of interpersonal relationships varies considerably, as do the individuals involved. Formal and informal caregivers in this study find themselves interacting within the complex VAMC healthcare system. Whatever the healthcare context, the need for relational support is essential to maintaining functional effectiveness of caregiving (Bisconti, Bergeman, & Boker, 2006; Dauenhauer, 2006; Gaugler, 2005; McIntyre, 2003; Port, 2006).

Recent caregiving research has placed more emphasis on the interpersonal, interactive processes of the caregiving situation and the need for greater focus on the "context of the care dyad" (Lyons & Sayer, 2005). Most of the archived case material in this study documents dyadic interactions. This emphasis on context considers the too often neglected hierarchical nature of the care dyad. Nagy's contextual theory anticipates shifting power dynamics and the need to reevaluate the appropriateness of caregiving processes due to changing transactional circumstances. Transactional dynamics that sustain veterans' formal and informal caregivers require reciprocity. Cases where there is a lack of emotional-relational support in the context of caregiving raise ethical concerns (Bergum & Dossetor, 2005).

This study reached grounded theoretical understanding of how relational ethics operate at the VAMC. Nagy's concepts provided a deductive element in this primarily inductive research. He proposed relational ethics as the heart of the contextual perspective since it provided the primary motivation to seek fairness in relational give and take (Boszormenyi-Nagy & Krasner, 1986). He explained that relationships remain healthy and mutually trustworthy only if there is reasonable exchange of earned entitlements fulfilled and acquired obligations met. Nagy believed our lives held untapped relational resources and reservoirs of trust accessible through applied relational ethics (Van Heusden & Van Den Eerenbeemt, 1987).

Formal caregivers and family members' beliefs and preferences are expressed in interactions regarding entitlements and obligations. The relational ethics of accumulated interactions potentially spreads within the VAMC caregiving environment as individual formal and informal caregivers seek validation and acceptance (Hargrave & Pfitzer, 2003). The time consuming and sometimes emotionally painful clarification of entitlements and obligations empowers care givers to express their needs and acknowledge the needs of others. More importantly it builds much needed reserves of trust and trustworthiness between formal and informal caregivers to deal with veteran's critical care, end-of-life, quality-of-life, and other ethical dilemmas.

Obligations and entitlements, both formal and informal, exist in situations where formal caregivers provide hands-on support while family members and long time friends provide relational and social support through a sense of obligations and/or earned entitlements from earlier interpersonal interactions (Dauenhauer, 2006; Gaugler, 2005; Port, 2006). Filial loyalty is a crucial dynamic. Every human being spends their first year obliged to someone for their very existence. That person is usually a parent that will one day grow old and need care (Boszormenyi-Nagy & Spark, 1973). According to Nagy and adult attachment theorists, later life filial relationships can provide especially powerful experiences in human development (Shemmings, 2006). Need for proximity, feelings of safety, and freedom from fear of separation can be mutually fulfilled by accepting our intergenerational obligations and honoring the earned entitlements of preceding generations (Van Heusden & Van Den Eerenbeemt, 1987).

Veteran's children were deeply involved in many of the cases in this study. Relational ethics highlighted the *rightness* of family members' continued involvement in the lives of aging loved ones after their placement in VAMC care. This and the pilot study confirmed that family

members do stay involved. Other research indicated a distinctive shift in the nature of family involvement (Gaugler, 2005). In home-based or community care, family members provided care unilaterally. In an institutional setting, such as the VAMC, there tended to be a shift to staff providing hands-on daily care while family members offered psycho-social support. Socio-emotional supports included, letter writing, cheering up or lifting spirits, and dealing with family guilt feelings (Gaugler, 2005). From Nagy's perspective, factors such as dealing with family guilt were part of maintaining relational equilibrium by honoring earned entitlements and merited obligations.

It is no small matter for caregivers to meet care obligations. Their role requires reaching beyond meeting ADL and IADL support needs. They are an indispensable part of preserving the subjective well being, quality of life, and identity of veteran loved ones in their time of greatest need. In Nagy's conception of what is ethical in vital human relationships, meeting obligations and acknowledging entitlements helps preserve the integrity of all involved.

Autonomy literature review. Sixty percent of the research population was over 65 years old, and 75% of veterans, or 9 of the 12, in study two were over 70 years old on their ethics committee referral date (ECRD). Many of the informal caregivers mentioned in case documentation were elders themselves. Most elders, including veterans and their caregivers, wanted to maintain their autonomy and not burden anyone; but elders can become burdened too.

Caregiving and support needs can place significant strain on family roles and relationships (Fauth, Zarit, Femia, Hofer, & Stephens, 2006). Spouses and significant others who find themselves in caregiving roles need emotional and logistical support just as availability of such relational support is decreasing (Perren, Schmid, & Wettstein, 2006). Autonomy perceived in relational terms (MacKenzie & Stoljar, 2000; Ryan & Deci, 2006) emphasizes the importance of relationships in both supporting and defining relational autonomy. MacIntyre (1981) makes the point that we cannot be autonomous beyond the context of social relationships.

It is through his or her membership in a variety of social groups that the individual identifies himself or herself and is identified by others. I am brother, cousin, and grandson, member of this household, that village, this tribe. These are not characteristics that belong to human beings accidentally, to be stripped away to discover "the real me." They are part of my substance, defining partially at least and sometimes wholly my obligations and my duties. Individuals inherit a particular space within an interlocking set

of social relationships; lacking that space, they are nobody, or at best a stranger or an outcast. (pp. 232-233)

Elder caregivers often experience contraction in their realm of relationships, whether by choice or circumstance. By choice, according to socioemotional selectivity theory, people tend to limit their relationships to those that are more emotionally supportive and meaningful (Carstensen, 1992). And through circumstance, relationship networks contract through losses related to mortality, limited mobility, and significant lifestyle changes (Neundorfer, McClendon, Smyth, Strauss, & McCallum, 2006). The challenges and stresses faced by care givers and recipients may be exacerbated by lack of emotional support. Their quality of life and perceived functional capability is significantly impacted by the quality of support provided by viable personal relationships (George, 2006). If informal caregivers' relational support needs are not met, it is likely that more of the caregiving burden will be shifted to an already overburdened professional care system (Cleary et al., 2006; Hancock, Woods, Challis, & Orrell, 2006).

Relational autonomy, as emphasized in this research, accepted the reality that we are autonomous persons who cherish the right of individual choice and decision, while remaining deeply social beings (MacKenzie & Stoljar, 2000). Caregiving choices, in hopes of resolving ethical dilemmas, were relational and made in concert with others invested in making the best possible decisions on behalf of veteran patients. Donchin (2000) argued for a reordering of bioethical theory to include a conception of autonomy that encourages healthcare professionals to consider the social circumstances of patients and their families. Further, she stated that in the context of clinical practice, personal autonomy should be understood as self-determining persons who are relationally positioned to family, intimates, and caregiving practitioners.

O'Neill (2002) continues the conceptual conversation regarding trust started by Nagy, connecting trust and trustworthiness in bioethics with principled autonomy. Contemporary bioethics sees autonomy as a matter of independence while principled autonomy sees autonomy as relational, selective, and graduated. Principled autonomy is relational in the sense of being autonomy *from* something, selective in that we may be independent in some circumstances but not others, and graduated since individuals have varying degrees of independence. She claims, and this research confirms, that trust flourishes between engaged persons, echoing perspectives of nurtured relational space (Bergum & Dossetor, 2005), and that, "Trust belongs to relationships and (mutual) obligations; individual autonomy with rights and adversarial claims" (O'Neill,

2002, p.25). She discusses the failings of individual autonomy and the principle-based reduction of bioethics in America to informed consent. Individual autonomy is seen as a minor aspect of principled autonomy that is relationally situated and rejects avoidable coercion and deception.

Study two and the relevant literature review confirmed the nature of the core category of relational autonomy as inherently relational and principled in its intentions.

Study Two Data Analysis

Study two explored a total of 72 primary documents for 12 selected veteran cases. The analysis produced a total of 323 separate codes, 20 code families, nearly 100 memos, and 4,703 code-related quotations. Four-stage grounded theory methodology (GTM, see Table 6 in Chapter 3, page 38) began with line-by-line coding, proceeded through category creation, constant data comparison, to identification of pivotal and core categories. Resultant grounded substantive theory was the agenda to advocate for relational autonomy. To maintain confidentiality, only case numbers (e.g. C8, C11, C23, etc.) were used to identify veteran patients, and all VAMC staff identifiers were removed.

All 25 veteran cases in the research were coded, categorized, and analyzed in study two. However, 12 of the cases more clearly exemplified the importance of interactions between formal and informal caregivers and thereby supported development of study two substantive theory. Those cases, with brief case descriptors, were:

| | | |
|--------------------------|---------------------|-----------------------|
| C2 – Lost Son | C3 – Unwilling NOK | C5 – Oxygen and Smoke |
| C7 – Pulled Tube | C8 – Cannot Let Go | C9 – Home to Die |
| C11 – Hospice Care | C12 – Family Agrees | C14 – Intensive Care |
| C23 – Opposed to Surgery | C24 – Mobility Care | C25 – Futile Care |

Analysis of data using *ATLAS.ti* reinforced selection of these 12 study-two cases, as presented in chapter four Table 12. The following statistics, copied from Table 12, confirm that family and spouse involvement was significantly more documented in study two cases. Twelve of 25 cases represented 48 percent of the research population which may understate some of the study two percentages presented, as explained in Table 12 footnotes in chapter four.

| Relational Codes (Informal and Formal) | S1 Data (13 Cases) | S2 Data (12 Cases) | ^a S1% of Total | ^b S2% of Total |
|---|-----------------------|-----------------------|------------------------------|------------------------------|
| REL:INFORML:FAMILY:INVOLVED | 158 | 234 | 40.3% | 59.7% |
| REL:INFORML:SPOUSE | 84 | 164 | 33.9% | 66.1% |

Stage one GTM analysis. Study two stage one analysis (see Table 6, Chapter Three), applying grounded theory methodology (GTM), started by coding and exploration of all formal-informal interactions, between VAMC staff and veteran’s family members and significant others. Line-by-line coding produced the code names shown in Table 14.

Table 14

Study Two Formal-Informal Relationship Codes

| Code | Coded for Interactions Between |
|-----------------------------|---|
| ETHICS:TEAM RECOMMENDATIONS | ECM-VSO |
| ETHICS:REFERRAL/CONSULT | Ethics committee members (ECM) and veteran’s significant others (VSO) |
| REL:FORML:CHP-FAMILY | Chaplin (CHP) and VSO |
| REL:FORML:DOC-FAMILY | Doctor and VSO |
| REL:FORML:DOC-POA | Doctor and Power of Attorney |

Table 14 (Continued)

| | |
|-----------------------------|---|
| REL:FORML:MED STDNT-FAMILY | Medical student and VSO |
| REL:FORML:NURS-FAMILY | Nurse and VSO |
| REL:FORML:PHYS ASST-FAMILY | Physician's Assistant and VSO |
| REL:FORML:SW-FAMILY | Social Worker and VSO |
| REL:FORML:VAMC-FAMILY | ^a Other VAMC Staff and VSO |
| REL:INFORML:FAMILY:INVOLVED | Any VAMC Staff and Any VSO; cross coded to insure relevant data inclusion |

Note. VSO = Veteran's significant others including family members, friends, intimates, etc.

ECM = Ethics Committee Members, disciplines including nurses, doctors, social workers, chaplins, etc.

^aOther VAMC Staff included administrative, financial, clerical personnel, etc.

Stage one coded the following relevant formal-informal communication data segments from selected cases. C3 (Unwilling NOK) was a World War II soldier whose family was only reluctantly involved. First doctor and social worker contacts with C3's family were recorded by a VAMC social worker. Researcher parenthetical explanations were in italics (*Italics*).

LOCAL TITLE: SOCIAL WORK NOTE DATE OF NOTE: NOV 30, 2006@09:57

He (*Dr. A, attending physician*) indicated that he had spoken to C3's son and requested that he come in to assist with decision making for veteran, but that his son had not yet agreed to come in. Called C3's son this morning on his cell # and updated him on his

father's status and informed him of the TEAM's (*ethics committee*) request for him to come to the VA so that they can discuss patient's status and prognosis with him.

Veteran's son indicated that he would come in today. He did not specify the time he would be here. This writer informed him that the TEAM is on call so Dr. A will be here all day. Veteran's son voiced understanding.

LOCAL TITLE: SOCIAL WORK NOTE DATE OF NOTE: DEC 05, 2006@10:10

Called son again and requested that he come in to meet with the TEAM (*ethics committee*) and discuss C3's code status given his very poor prognosis, per Dr. A's request. Veteran's son reported that he was here last Thursday and met with a doctor in the ER (*Emergency Room*), although he did not recall her name. C3's son reported that he wants his father to be a full code (*Aggressive care intended to keep the veteran alive, less concern with quality of life [QOL]*) and he was told on Thursday that he did not need to come in and meet with Dr. A since he spoke with an ER doctor at that time. This is the second request by the undersigned to have the son come in and meet with the TEAM to discuss his father's care and he continues to refuse.

LOCAL TITLE: SOCIAL WORK NOTE DATE OF NOTE: DEC 06, 2006@16:14

Received a phone call from C3's son this afternoon. This writer and Dr. A spoke with him and explained veteran's critical condition and poor prognosis. Veteran's son voiced understanding and stated that he does not want his father to suffer and he understands that C3 will more than likely not benefit from resuscitation. Dr. A spoke with veteran's son and after explaining what a full code entails, veteran's son decided to make veteran a DNR (*Do Not Resuscitate, in simple terms, to allow the veteran to die if another health crisis overtook him*). He expressed his and his mother's desire to keep C3 as comfortable as possible. Veteran's son expressed his understanding of what it means to have his father as a DNR status and has decided that this is the best option for him at this time, given his medical condition. Will f/u at ECRC tomorrow.

This one week series of interactions were line-by-line coded for the indicated interactions between the VAMC doctor and social worker and the veteran's son. Two different agendas were clearly implied. Initially the son wanted full code care, meaning everything possible should be

done to keep his father alive. However, the son was not willing to have a face-to-face meeting with VAMC ethics committee/team; there was no way to determine the reason why. The VAMC staff was more focused on the veteran's poor quality of life (QOL) and very poor prognosis. By December 6th both the veteran's son and mother were in agreement that comfort care was the more ethical choice. The advocacy of the VAMC staff and the Team (ethics committee) influenced the family to reconsider their choice of full code care. These insights anticipated stage two and stage three analyses and helped identify core categories in stage two for axial coding in stage three.

Another example of stage one coding was for C5 (Oxygen and Smoke), an Air Force Vietnam era veteran. He was relatively young, as one of two veterans in study two, and one of four in the research population, who were in their forties as of the ethics committee referral date (ECRD). The issue of controversy in the case was the veteran's desire to smoke and the difference in agendas and advocacy between the formal and informal caregivers. These four entries occurred during the month of October 2006.

LOCAL TITLE: SOCIAL WORK NOTE DATE OF NOTE: OCT 02, 2006@09:36:01
SW (*Social Worker*) informed by CHN (*Community Health Nurse*) that C5 can not return to Xxxx Retirement Home due to o2 (*oxygen*) needs; C5 now qualifies for nursing home care. Undersigned contacted BW at Xxxx Retirement Home to advise of same. SW spoke with vet's mother, who is vet's fiduciary and POA. SW discussed the information regarding vet's assessed need for a higher level of care and the necessary financial arrangements that she will likely need to secure in the near future. Discussed her securing a pre-paid, irrevocable burial for veteran with monies she has in a CD for him. Vet has no burial plans in place as yet. Also, discussed her securing current bank statements and exact income data in order to complete the Medicaid application. C5's mother asked undersigned to relay this info to her daughter Ms. Kxxx (as she is legally blind). SW (*Social Worker*) relayed all above info also to Ms. Kxxx... SW provided both vet's mother and sister with the unit SW name and number and advised that she would be calling for follow-up regarding the nursing home placement process.

LOCAL TITLE: COMMUNITY HEALTH NURSE NOTE

DATE OF NOTE: OCT 04, 2006@09:41

Call from Lxxx, MSW (*Masters in Social Work*) that mother and sister want veteran to return to Xxxx Adult home with only O2 (*Oxygen*) at night and not continuous due to wanting veteran to return to same environment and not go to another home. C5 is independent in ADL's. Respiratory status and smoking safety are the means to determine level of care. Called administrator of Xxxx adult home and he states he wants a statement that the issue of not using oxygen could cause further decline and that the family is aware of this choice and that they cannot control veteran obtaining cigarettes although they discourage smoking. Residential Home administrator states that they cannot accept C5 back to facility with continuous oxygen and that he can have oxygen via concentrator in his room.

LOCAL TITLE: SOCIAL WORK NOTE DATE OF NOTE: OCT 12, 2006@10:35

Consulted with Dr. Yxxx, Dr. Mxxx this a.m. Dr. Mxxx consulted with Dr. Nxxx regarding oxygen need for vet. Per Dr. N, vet does not need oxygen while resting - therefore not needing at night. Contacted C5's mother to update - she understands and agrees with discharge plan (back to Xxxx Retirement Home without oxygen). Xxxx Retirement Home will pick vet up this afternoon - requested discharge instructions and order. Updated staff.

LOCAL TITLE: SOCIAL WORK NOTE 10/30/2007 14:00

C5 continues to be able to get his medical, emotional and social needs met at the current level of care. Ms T (*Resident Home Staff*) reports that veteran continues to have occasion emotional outbursts which are generally ignored by peers and re-directed with good outcome by staffers. C5's mother calls monthly and writes, and veteran will occasionally initiate calling mother but does get assist with dialing phone. The assigned community residential care program social worker will continue to provide on-going case management for this veteran while a resident at this home.

Again, stage one coding noted the shifting agendas and advocacy of VAMC staff and veteran's family members. In this case there were also services related to, but outside of the VAMC, involved. However, agendas and advocacy reached agreement within the VAMC context with the entry of October 12th when a doctor qualified the need for oxygen. It is

interesting that there were more conflicted entries advocating the veteran's right to smoke cigarettes versus VAMC staff agenda to have the veteran stop smoking so he could have oxygen and be successfully discharged to the residential home prior to the October 12th document.

Stage two GTM analysis. Stage two analyses built on stage one concepts, further abstracted relational ethics issues related to agendas and advocacy, created categories, and reached the point of maximum complexity through continuous data and categorical comparisons. Analysis of the 12 selected cases further abstracted data analyses and created the following five primary code categories: Formal-Informal Relations, Ethics Recommendations, Advanced Directives, EOL/QOL Issues, Psychosocial Elements, and Caregiving Agendas. The five categories, reduced and refined from 20 earlier conceptual categories, are shown in Table 15.

Table 15

Study Two - Stage Two GTM Analysis Categories

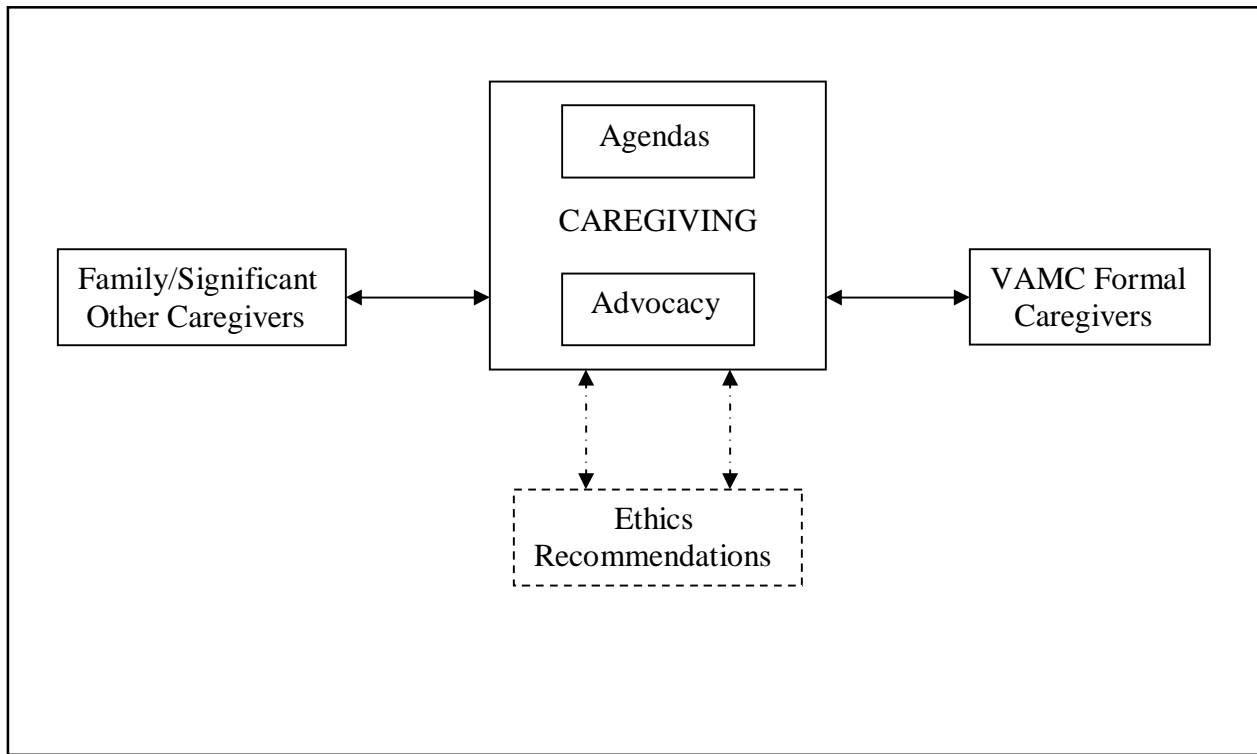
| Categories | Properties | Dimensions |
|---------------------------|-------------------|---|
| Formal-Informal Relations | Collaborative | Various degrees of collaboration, congruence, between formal and informal caregivers. |
| | Conflicted | Various degrees of conflict, disagreement, or incongruence, between formal and informal caregivers |
| Ethics Recommendations | Support Staff | Degree congruent with VAMC Staff |
| | Support Family | Degree congruent with Family/Others |
| Advanced Directives | Care Requested | Degree of detail in documented care requests |
| | Care Withheld | Degree of detail in documented care precluded |
| Psychosocial Elements | Affective | Subjective degree of rational versus emotional choices impacting care trajectory |
| | Social/Relational | Degree of impact of social/relational case elements on care trajectory |
| Caregiving Agendas | Cure | Cure = Standard procedures and actions by VAMC staff to cure veteran's medical problems, and may include full-code, aggressive testing, surgery, medications, and procedures |
| | Comfort | Comfort = EOL/QOL dimensions, veteran's condition terminal in less than 6 months, palliative or hospice care indicated, usually includes a DNR (Do Not Resuscitate) care code |

Stage three GTM analysis. As study two transitioned to stage three analyses the data was reassembled, core axes identified, and linkages established between categories that clarified relational processes of formal and informal caregivers' advocacy for their respective agendas. There was adequate coded data to support differentiation of advocacy and agendas. There were two underlying conceptual axes in all 12 cases, congruence, as presented in the coded stage-one data segments, and relational autonomy, as exemplified in pilot study C9 (Home to Die), and reviewed in data to follow. Documented relational processes sought congruence between formal and informal caregivers' agendas and advocacy whenever possible. And all participants in the process sought congruence with veteran's chosen care values and preferences, according to caregiver perspectives on the appropriateness of those autonomous preferences.

The five abstracted primary categories from stage two analyses were linked to relational processes shown in Figure 3. Study two focused on documented interactions in the formal-informal relational channel. Caregivers and ethics committee members had agendas and advocated for those agendas according to role commitments, role salience, and their respective role hierarchies. The main relational communication channel was between formal and informal caregivers. However, in all study two cases the ethics committee was involved, provided assessment, and made recommendations. Therefore each participant in Figure 3 potentially impacted advocacy and agendas of all others involved.

The categories of Table 15 provided and informed elements of Figure 3 relational processes. The Formal-Informal category represented the relational communication channel linking professional and family/significant other caregivers. Ethics Recommendations by ethics committee members and others, influenced, and were influenced by, the agendas and advocacy of caregiving others. Advanced Directives, depending on extensiveness and specificity, strongly influenced caregiving agendas and advocacy. Psychosocial Elements impacted all participants but presumably professional caregivers maintained a more consistently objective and rational stance, while the affective nature of intimate relationships were more likely to include emotional motivators for informal caregivers. Caregiving Agendas, and related advocacy, either impeded or enhanced relational and decision making processes between formal and informal caregivers.

Figure 3. Study Two - Stage Three Relational Processes



Core axes of agenda and advocacy, C8 analyses. Analysis of C8 (Cannot Let Go) provided a good example of the operation of core axes of advocacy and agendas involving formal and informal caregivers. This veteran sailor served in Vietnam and was one of the three veterans who were still alive at the time of study two. C8's case also presented aspects of the underlying axes of congruence and relational autonomy. This veteran was suffering from Lewy Body Dementia (LBD) described as follows.

Central feature: Progressive dementia - deficits in attention and executive function are typical. Prominent memory impairment may not be evident in the early stages. Core features: Fluctuating cognition with pronounced variations in attention and alertness. Recurrent complex visual hallucinations, typically well formed and detailed. Spontaneous features of Parkinsonism (Lewy Body Dementia Association, 2008).

Although the ethics committee referral date (ECRD) was 3/22/06, a recorded consult by a VAMC PhD staff psychologist from 2001 provided the first assessment and diagnosis of LBD. 'ALL CAPS' format was retained from the original entry.

LOCAL TITLE: NEUROPSYCHOLOGICAL CONSULT

DATE OF NOTE: JUL 24, 2001@09:41:28

IT SEEMS LIKELY THAT THIS IS A CASE OF LEWY BODY DEMENTIA, PROBABLY COMBINED WITH ALZHEIMER'S DISEASE (i.e., THE "LEWY BODY VARIANT OF ALZHEIMER'S"), WITH THE APHASIA PROBABLY BEING DUE TO THE LATTER. NO PARKINSONIAN PHENOMENA WERE NOTED OR COULD BE ELICITED, BUT C8 SEEMS TO HAVE BEEN EXPERIENCING VISUAL HALLUCINATIONS, AND THE DAY-TO-DAY VARIABILITY IN C8'S CONFUSION APPEARS TO BE IN LINE WITH ONE POSSIBLE MANIFESTATION OF 'FLUCTUATIONS'. (HIS WIFE WASN'T CERTAIN AS TO WHETHER THE MORE PHASIC MINUTE-TO-MINUTE VARIETY WAS PRESENT OR NOT, BUT ONE WONDERS ABOUT THOSE FALLS, THE 'SYNCOPAL' (*fainting*) EVENTS.) C8'S HISTORY OF ANOSMIA (*inability to smell*) SEEMS TO BE RELEVANT HERE, AS WELL, IF WE CAN RULE OUT A BRAIN TRAUMA ETIOLOGY (*cause of disease/problem*) FOR IT---AND I THINK THAT WE CAN, SINCE THERE IS NO CONVINCING EVIDENCE THAT THE BLOW TO THE PATIENT'S HEAD BY THE CHUNK OF WOOD RESULTED IN A TRAUMATIC BRAIN INJURY, AND THE REPORTED TOPOGRAPHY OF THE BLOW DOES NOT FIT WITH WHAT WOULD BE NEEDED TO SIGNIFICANTLY DAMAGE THE OLFACTORY BULBS. HIS ANOSMIA IS RELEVANT BECAUSE A RECENT ARTICLE HAS LINKED IT TO THE PRESENTATION OF LEWY BODY DEMENTIA, FOR WHICH IT SEEMS TO BE A MORE RELIABLE MARKER THAN FOR 'PURE' ALZHEIMER'S (SEE McShane et al. J. Neurol. Neurosurg. & Psychiatry 2001;70:739-743.). GIVEN ALL OF THE ABOVE, A TRIAL OF AN ANTICHOLINESTERASE SEEMS TO BE THE WAY TO GO. IN ADDITION, HE AND HIS WIFE WANT AND NEED INFORMATION ON SOCIAL-LEGAL MATTERS, SUCH AS POWER OF ATTORNEY, GUARDIANSHIP OF PERSON, ETC.

The staff psychologist recorded a medication agenda to help ameliorate dementia symptoms and advocated that information be provided to the veteran and his wife. The following social worker entry came two years later. The researcher did not discover any documentation of

intervening actions by VAMC staff. In spite of the lag time the response is clearly congruent with veteran and wife's request and the psychologist's advocacy on their behalf.

LOCAL TITLE: SOCIAL WORK CONSULT DATE OF NOTE: JUL 16, 2003@09:40

SW SPOKE WITH PATIENT'S SPOUSE VIA PHONE RELATIVE TO CONSULT FOR LTC (*Long Term Care*) PLANNING. MRS C8 INDICATED THAT SHE IS PLANNING STAGES OF LTC FOR SPOUSE DUE TO CONTINUED FUNCTIONAL DECLINE. PROVIDED MRS C8 WITH INFORMATION ON PLACEMENT OPTIONS RELATIVE TO MILL BILL (*Millennium Bill, law passed in 1999, mandates VA to provide needed nursing home care to veterans who are at least 70 per cent service-connected for nursing home care*) AS PATIENT IS 100%SC (*Service Connected Care*). EDUCATION PROVIDED ON RESPITE CARE @VAMC. PROVIDED THIS WRITER'S NAME/PHONE NUMBER FOR FUTURE USE AS NEEDED. SCHEDULED APPOINTMENT TO FURTHER DISCUSS LTC OPTIONS FOR 8/14/03@14:00

By June of 2004 the situation had changed as indicated by a staff physician's request for psychiatric consult.

LOCAL TITLE: PSYCHIATRY CONSULT REQUEST DATE: JUNE 28, 2004

Reason For Request: 71 year old with end-stage Lewy Bodies variant of Alzheimers, C8 at this point bedridden, feed by wife/staff. No acute medically issues, wife desires long-term placement at the VAMC as she can not handle care for C8 anymore.

The following response was recorded a few days later.

LOCAL TITLE: PSYCHIATRY CONSULT DATE OF NOTE: JUL 02, 2004@16:24

C8's medical record reviewed and also seen by Physician's Assistant. Found that he is not a good candidate for the VAMC program. C8 has advanced dementia and needs a nursing home level of care at this time. He has no behavioral issues that would require inpatient care at present. Thank you. Signed, MD, Geriatric Psychiatrist

These two entries recorded C8 wife's advocacy and agenda to have long term placement at the VAMC. However, VAMC staff determined that such level of care was not warranted at the time and suggested private nursing home care, indicating a lack of congruence of agendas.

The following entry indicated psychosocial category coding with the attribution of affective motivations to family's ambivalence. The implied agenda of VAMC staff was to have the veteran's care status changed to DNR while C8's wife resisted DNR care status and requested placement of a feeding tube.

LOCAL TITLE: Discharge Summary

DATE: AUG 01, 2004@10:49

Shortly after admission, several lengthy discussions took place in which physicians on the team offered their support in decision making with C8's wife and brothers (wife is MPOA, *Medical Power of Attorney*). Mrs C8 has been reluctant to make C8 a DNR (*Do Not Resuscitate*) due to feelings of guilt and optimism about return of his functional status. She also strongly desired placement of a feeding tube, which was placed during this stay. Shortly after the initiation of TF (*tube feeding*), C8 developed high residuals, cellulitis (*infection*) at the Peg (*feeding tube*) site, and an elevated WBC (*White Blood Cell count*). Signed, MD, Attending Physician

Again, there was documented incongruence of agendas. Documentation 18 months later indicated increased advocacy and agenda incongruence.

LOCAL TITLE: SOCIAL WORK NOTE

DATE OF NOTE: MAR 22, 2006@14:14

Contacted C8's wife per request of Dr Mxxx to arrange for a time for the Ethics Committee to meet with her. The wife stated that she cannot come any during the week until school is out. Furthermore she went on to say that she was "not going to sign those papers anyway." She stated that she knew the reason for the meeting was to discuss not providing vet with all care that he might need and that she would "not do anything to prevent him from a day of life." The wife related that she felt the vet was functional and responded to the family and that until he became brain dead she did not want to change the course of treatment or plans for him. MD informed of the above.

An ethics committee consult/referral entry was made the same afternoon. C8 was a 100 percent service-connected care veteran. This case lent credence to Dr. Kim's observation that a rating of 100 percent may empower agendas and advocacy for more aggressive care for a longer period of time than may be warranted, given quality of life and resource use issues. Even in cases where the veteran indicated a desire for comfort care only, in circumstances where 100 percent coverage in place, there seemed more of a tendency for significant others to demand more care. The lack of any financial burden on veterans' significant others, along with the fact that military

family members and others make sacrifices related to the veteran's military service, may have contributed to this phenomenon. The sample wasn't large enough to make any definitive statement regarding this phenomenon.

As in study one, important psychosocial and relational information was recorded in addendums to standard data entries.

LOCAL TITLE: ETHICS REFERRAL DATE OF NOTE: MAR 22, 2006@15:35

*** ETHICS REFERRAL Has ADDENDA ***

Disciplines Present: Attending, Resident, Social Work

Reason for Referral: Discussion of the Code Status with the patient's wife.

Brief Clinical History: 73 y.o. male with what appears to be end stage dementia, who is unresponsive to verbal stimuli, being fed via PEG. Multiple readmissions due to recurrent PNA (?) (possibly aspiration related). Signed, MD, ATTENDING PHYSICIAN

03/28/2006 ADDENDUM STATUS: COMPLETED

C8's wife refused to meet with the Ethics Committee. For additional information refer to social work progress note of this date (*Shown above*).

Exploration of CPRS data yielded no further entries indicating ethics committee involvement or follow up. By the end of 2007 the situation had changed. C8's 100 percent service connected rating qualified him for nursing home care at the VAMC. At this point family and VAMC staff agendas and advocacy became more congruent. C8 was admitted for long term care at the VAMC nursing home.

LOCAL TITLE: Discharge Summary DATE: DEC 10, 2007@11:46

C8 is a 75-year-old white male with past medical history significant for advanced dementia, probable Lewy body type, was brought to the Emergency Room on 06/24/04 due to acute change in behavior. The patient had previously been diagnosed with dementia and was able to speak in short sentences, but at the time of admission could only put two words together and he was no longer able to be transferred from bed to toilet by his wife. Workup on Acute Medicine reveals no acute findings. The patient is 100% service-connected and is currently being admitted under the Millennium Bill (*law passed in 1999, mandates VA to provide needed nursing home care to veterans who are at least 70 per cent service-connected*).

However, questions of quality of life (QOL) remained as the veteran's health continued to deteriorate. A brief data segment from a medical consult in March of 2008 gave some insight into C8's medical condition and likely QOL.

LOCAL TITLE: GASTROENTEROLOGY CONSULT

DATE OF NOTE: MAR 06, 2008@11:30

Requested removal of PEG tube because the rubber tubing is rotten and rupture is imminent. PEG initially placed in 2004 and was never changed. Veteran with significant dementia. Abdomen examined, gastrostomy tube noted in the upper abdomen, rubber is indeed worn off and tube will be broken up soon; gastrostomy tube insertion site was cleaned under sterile fashion, the tube was pulled out, while pulling the tube out the rubber broke, leaving the bumper inside the stomach.

Without more recent evidence in the documentation it was impossible to tell if the situation had changed since the entry in March of 2008 when C8's wife refused to meet with the ethics committee. It was presumed that the wife's status as Medical Power of Attorney meant that her agenda for long term care at the VAMC and advocacy for full code care held sway.

Stage four GTM analysis. The transition from stage three to stage four in study two was anticipated in stage three analyses discussed in the preceding section. However, the significant shift was towards identification of the core category of relational autonomy, as defined in chapter one and discussed in the literature review in this chapter. This led to selective coding of all 25 cases in the research population for autonomy as well as recoding for a combined agenda/advocacy category. Selective coding of the 12 study two veteran cases produced 491 coded quotations for the core category of autonomy and 106 quotations for core axes of agenda and advocacy.

There was an understanding that the categories of agenda and advocacy represented a partial reframe of the concept of agency central to study one, since agency was related to the documented exercise of relational advocacy and agendas. Agency in study one was related to efficacious choice making, veteran's mental and physical capacity, and agentic negotiation. Whereas agendas and advocacy considered what case elements were emphasized and how the intentions of agendas were communicated. The differentiation between agency, agendas, and advocacy was important to understanding the separate and important conceptual categories that promoted relational ethics substantive theory development in study two.

Presented now is detailed stage four analysis for C11 (Hospice Care), a Navy veteran from the post Vietnam era, C24 (Mobility Care), a veteran soldier, and C25 (Futile Care) an Air Force veteran. Both C24 and C25 were Korean War veterans and 74 years old at the time of their ethics consult; C11 was a relatively young 48 years old. Stage four developed substantive theory of agenda to advocate for relational autonomy and presented one quadrant of an integrated model of relational ethics in caregiving for veterans presented in detail in chapter six. C11 was assessed as part of a psychiatric consult and effectively advocated for his agenda. He expressed appropriate relational autonomy in the recognition, documented on line five, that his wife needed time to herself even though he was missing her. He also stated positive agendas to participate in VAMC activities and for a future at home with his wife in their remodeled house.

LOCAL TITLE: PSYCHIATRY CONSULT DATE OF NOTE: SEP 21, 2005@08:11

During interview this morning C11 reports that he got good sleep last night, has been having adequate tube feeds and is adjusting to the new surroundings. When questioned about his depressive symptoms he replied "who wouldn't be?" C11 soon added that he was somewhat disturbed yesterday due to being in the hospital as he was missing his wife but he also understands her need to have some time by herself. He endorsed to having long standing difficulties in controlling his emotions and being easily tearful but he attributes that to the illness. C11 denies any thoughts of hurting himself. He also reports that he was somewhat more anxious yesterday than his baseline but feels good today. Reported his mood as a 6 on a scale of 10 and said that he was excited about participating in the activities on the floor including music therapy. He talked about the current remodeling of his house so that it is better adapted for his wife to take care of him. He anticipates his hospital stay to be a little over 2 weeks and then is looking forward to getting back into his routine at home with his wife. C11 reports that he has been doing pretty good on the medications given by his psychiatrist, Dr. Txxxx. His anxiety and depression are fairly under control and he tolerates the meds well. Denies excessive drowsiness.

A couple of months later VAMC staff reported a consult that advocated for C11 and wife's agenda to provide hospice care at home, with home health providers to assist as needed. The good news was that the consult assessment estimated that C11 had less than 6 months to live. In actuality, without violating confidentiality on date of death, the veteran lived for

something over one year after going home with hospice support. It was important to consider that a prognosis of less than six months to live was one of the necessary, but not sufficient, conditions to qualify for hospice care.

The course of this case involved several more hospitalizations including two to provide respite for C11's wife, his full time informal caregiver. Again, there was documented congruence between formal-informal caregivers with the VAMC supporting informal caregivers with two weeks of respite care twice per year, understanding that without respite, caregivers were unlikely to be able to continue with long term, at home care. In this case the veteran, his wife, and VAMC staff were congruent in their agendas and advocacy to support what was deemed to be the relationally autonomous desire to be cared for at home, as much as possible, until death.

LOCAL TITLE: HOSPICE/PALLIATIVE SERVICES CONSULT

DATE OF NOTE: NOV 23, 2005@12:09

Physician/Provider Recommendations: Per C11's request, veteran would like to have hospice care and does not want to be in the hospital again. He has neuromuscular disease, failure to thrive, multiple admissions for infections. If untreated, will be fatal.

The patient should meet the following criteria:

| | |
|---|-----|
| Life limiting/terminal condition | Yes |
| Patient/Family informed condition is life limiting/terminal | Yes |
| Patient/Family elected palliative care | Yes |
| Patient/Family aware of referral to Hospice | Yes |

Documentation of clinical progression of disease:

Evidenced by: Multiple emergency room visits, Inpatient hospitalizations
AND/OR, Recent decline in functional status: Requires considerable assistance and frequent medical care, Disabled; requires special care and assistance. Unable to care for self; disease may be progressing rapidly.

AND/OR Dependence in 3 of 6 Activities of Daily Living: bathing, feeding, transfers, continence of urine and stool

AND/OR Recent impaired nutritional status:

Evidenced by: unintentional, progressive weight loss of 10% over past six months

| | |
|--|-----|
| Rapid decline in physical or functional status in spite of appropriate treatment | Yes |
|--|-----|

Symptom severity that with reasonable reliability is consistent with a lifespan prognosis of six (6) months or less. Yes Signed, RN, Registered Nurse

Another entry in November 2005 listed a spiritual-medical agenda that the VAMC documented and honored, “Of note, the patient is a Jehovah's Witness and does not want blood transfusions.”

The following discharge summary provided an excellent overview of case history and circumstances over a year after the ethics committee referral and consult. The tone of the summary conveys a sense of collaboration and congruence with phrases like “a pleasant but unfortunate gentleman” and “his devoted wife” was mentioned twice in those terms. It explained the cooperative agendas of the formal and informal caregivers in meeting the veterans changing needs. Therefore, home hospice care was interspersed with several hospitalizations as his health deteriorated. This veteran sailor passed away at home, per his wishes, not long after this final discharge summary.

The summary noted the congruence of caregiver agendas in honoring appropriate levels of autonomy and care. C11’s wife “noticed on her visits that her and her husband's hospice care goals were being met” and, “the interventions were felt to be effective per the team and wife.” Near the end of the summary was a final indication of congruence between formal and informal caregivers in meeting the relational autonomous wishes of the veteran. There were also implications in the documentation that the veteran and his wife were effective in the way they advocated for their care wishes. VAMC staff consistently validated family involvement.

LOCAL TITLE: Discharge Summary

DATE: FEB 06, 2007

C11 is a pleasant but unfortunate gentleman who was cared for at home by his devoted wife. He was receiving home hospice care. He had previously been admitted for a respite under the hospice program to the long-term care setting. He is followed by Dr. Hxxx in the outpatient clinic. C11 was admitted to ECRC (*Extended Care and Rehabilitation Center*) from the acute care setting to provide hospice care. His wife was devoted. She was well aware of his treatment wishes as well as his medications. During his stay on ECRC he was followed in the weekly palliative care treatment rounds. His tube feedings were continued in the hospice care setting. Treatment goals were felt to be met by the members of the board team as well as the palliative care team making rounds. His wife visited frequently. She noticed on her visits that her and her husband's hospice care goals

were being met. Medication adjustments were made after discussing these changes with the team and the wife and the interventions were felt to be effective per the team and wife. Within the past week C11 noted an increased difficulty handling secretions. His wife came in. It was felt clinically that he had pneumonia. The wife reiterated her DNR as well as her other treatment limitation requests to comfort supportive measures only. Scopolamine was added to help manage his upper airway secretions. Morphine (*often for pain management near EOL*) was also added p.r.n. (*on request*). His clonazepam p.r.n. dose was continued. The wife had friends at the bedside and all felt that the treatment interventions were affective as did the RNs (*Registered Nurses*). His wife noted that the patient had requested to return home for end of life care. She noted she felt comfortable continuing the inpatient hospice care plan as an outpatient. This was discussed with the RN who agreed. She was seen by the PA (*Physicians Assistant*) social worker and the dietician prior to discharge. Home health was consulted and home hospice care was arranged.

C24's case presented a longitudinal exploration of changing levels of relational autonomy as this veteran soldier's mental health deteriorated. The earliest documented snapshot was taken from a discharge summary in 1996, over seven years prior to the ECRD of October 8, 2003. The final document shared was from March of 2008. Holding true to the initial research strategy, this 12-year window far exceeded estimated research timeframe parameters in following the data trail where the story led. The following entry indicated compromised capacity which impacted appropriate levels of autonomy given potential danger to others in need of care. This entry also documented care outside of the VAMC. The documentation established an early functional baseline for C24.

LOCAL TITLE: Discharge Summary

DATE: JUN 19, 1996

C24 is a 67-year old, black male who was admitted from Cxxx Home for Adults because they felt they could no longer care for him. He had been there for many years because of behavioral problems which had been resistant on and off to inpatient and outpatient therapy. Specifically, he was exposing his genitalia, was more irritable with outbursts of anger, during which time, he would strike out at persons who made him angry without a clear precipitant. He had verbal angry outbursts, mood swings from giggling and laughing to being very quiet and withdrawn. The staff at the home for

adults stated that he was abusive to other residents, exhibited his anger by hitting his fist in his hand, glaring, complaining to staff, "You spit in my mouth", responding to auditory hallucinations. He was noted to be very compliant with medications. The above was a change in his baseline during which time he was very pleasant and cooperative, keeps to himself, is extremely soft-spoken, does not socialize much, but, again, is pleasant and cooperative at baseline.

The following entry from 2003 indicated the mental health problems that impacted formal and informal caregivers' determination of agendas and advocacy that met, but did not exceed, appropriate levels of veteran autonomy as the years progressed. It also helped explain the behavior described in the 1996 discharge summary.

LOCAL TITLE: STAFF PSYCHIATRIST NOTE DATE: OCT 20, 2003@15:42

AXIS I: (*diagnostic axis from the Diagnostic and Statistical Manual of Mental Disorders, 4th edition, DSMIV*)

- 1) Dementia not otherwise specified with behavioral disturbance
- 2) Schizophrenia, residual, continuous.

Note that C24 is 100% Service Connected from the Veterans Affairs for schizophrenia. Hence he has carried that diagnosis since he was a young man, young enough to serve in the military.

The above documents set the scene and established the necessity for formal and informal caregivers to advocate for agendas that would provide relational autonomy for the veteran. In SSSI terms, this process, as seen from the named and classified worldview of the formal caregiver, provided the least restrictive level of care; that level was negotiated between formal and informal caregivers.

The following ethics referral and ethics committee follow up advocated for the family to seek guardianship, which was pursued by the veteran's niece. The key issue at the time of ethics referral was foot care for the veteran to maintain his mobility. The veteran's autonomous desire to not have his feet cared for seemed inappropriate given the ethical issues of maintaining his mobility and placement in the only home he had known for many years. The necessity to advocate for an agenda that supported more relational autonomy seemed clear. If podiatry care was maintained so was the least restrictive level of care, and in the long run, an increased level of relational autonomy.

LOCAL TITLE: ETHICS REFERRAL

DATE OF NOTE: OCT 08, 2003@15:43

C24 is a 74 year-old, 100% SC veteran who resists podiatry care which is necessary to keep him ambulatory and pain free. Caregivers are hesitant to order inpatient intervention due to his resistance, but are also concerned about seeing that his needs are met in an appropriate setting. C24 has been a resident at a Community Residential Care home, which is basically the only home he knows, for over 10 years, and is followed by MHC (*Mental Health Care*) and PPCT (?). His family had had very limited involvement. He has Mental Illness which is well documented. He has foot care needs that require consistent, regular podiatry intervention for the past several years. As of this past year podiatry care has not been done because he has become more difficult to treat with the present intervention due to discomfort as well as fear. He has required pre-procedure medications for anxiety. He has had a recent hospitalization after he became non-ambulatory in the community home because his feet were painful. He cannot stay at this level of care if he is non-ambulatory and nursing home placement is unlikely due to his Mental Illness.

The ethics team, in a follow-up meeting a couple of days later, advocated developing a shared agenda with adequately informed family members to weigh the risks and benefits of proposed podiatry surgical procedures.

LOCAL TITLE: ETHICS TEAM FOLLOW-UP

DATE: OCT 10, 2003@13:30

Observations: There are indications from veteran's family that they would like to continue podiatry care. There are also indications by care providers that increased pain issues and discomfort of veteran's feet are occurring more frequently.

Team Recommendations: Encourage family to pursue guardianship. Also, to encourage providers to seek further assistance in laying out risks associated with surgery. It was suggested by this committee to have provider do a surgery consult with Dr. Wxxx to identify risks. Such information will be helpful when guardianship is established unless otherwise considered by family for treatment and care of veteran.

The first documented identification of informal caregiver with the legal power to act as guardian and advocate follows.

Local Title: ADVANCE DIRECTIVE

12/16/2003 12:06

Ms Xxxx (*veteran's niece*) brought me a paper that looks official. It is a certificate /letter of qualification from the Bxxx Co circuit Court. That as of the 20th day of Nov 2003, she has qualified as GUARDIAN OF THE ESTATE OF C24, incapacitated. Court file no: Xxxx.

It is my understanding that this makes her able to make medical decisions for her uncle.

Signed by: MD, STAFF PSYCHIATRIST 12/16/2003 12:10

Family relationship with the veteran was clarified in an addendum, three weeks later.

Local Title: ADDENDUM

01/06/2004 12:15

Ms. Xxxx, vet's niece has been appointed by the Bxxx County Court as veteran's legal guardian of person effective 11/18/03. Her address is, Home phone , cell phone

Signed by: MSW, SOCIAL WORKER 01/06/2004 12:18

This presentation for C24 ended with social worker contacts with family members that questioned documentation of October 8th indicating that "His family had had very limited involvement;" and a final discharge summary from March 2007 that indicated years of least restrictive level of care that supported veteran's relational autonomy following the presented collaborative intervention by formal and informal caregivers. The veteran had his feet cared for and returned to assisted living with periodic VAMC care when needed.

LOCAL TITLE: SOCIAL WORK NOTE DATE: OCT 10, 2003@08:30:12

C24 is a 74 y/o, 100 S/C resident of Cxxx Assisted Living Facility, a CRC affiliated licensed home for adults. C24 has been a resident of Cxxx for over 20 years. In speaking with his most involved NOK this am, Mr. Xxxx, C24's brother has indicated that the veteran has always had a problem with his feet and callous build up. The family is most interested in the veteran continuing with treatment for his foot condition and maintaining his current placement so that he can function as independently as possible. The family will be discussing this with other siblings of vet.

Also vet's niece, daughter of Mr. Xxxx, is Ms. Gxxx who has on-going contact with vet. She is also an employee at a State Psychiatric Hospital. Undersigned will be speaking with her after the Ethics Committee meets to review the outcome and tx (*treatment*) plan with her. SW will continue to provide case-management services for vet as needed.

Signed, MSW, SOCIAL WORKER, 10/10/2003 09:43

10/10/2003 ADDENDUM

STATUS: COMPLETED

Ms. Gxxx called back to say that she and her father, Mr. Xxxx (the vet's brother) would like to be here at VAMC with the vet when he does have surgery on his feet. She states that she also has a strong bond with the vet and feels that it would be more comforting to him to know that family were here for him.

Signed, MSW, SOCIAL WORKER, 10/10/2003 11:00

The discharge summary indicated that veteran had more than three additional years (until February of 2007) of relatively autonomous living at the adult care home due to the presented formal-informal collaboration, as moderated by the VAMC ethics committee.

LOCAL TITLE: Discharge Summary

DATE: MAR 19, 2007@12:17

C24 is a 77-year-old African-American male with a past history of severe dementia and chronic schizophrenia, who was admitted to ECRC on February 28, 2007 after being transferred from an adult care home. The patient had been paying privately at Axxx Rehab, and under the Millennium Bill he is eligible for long-term care. C24 was admitted from Axxx Rehab and Healthcare under a contract deal with the VA.

C24 exemplified the relational processes shown in Figure 3. Interactions between formal and informal caregivers demonstrated relational ethics in advocating an agenda that provided relational autonomy for this Korean War veteran.

C25 (Futile Care) was a widower and veteran of the Korean War era with two sons and a daughter-in-law actively involved in his caregiving dilemmas. One son and his wife lived near the VAMC, were very engaged, and visited often. The other son lived several states away and was kept informed by his brother and sister-in-law. In contrast to the longitudinal view of C24, all documentation presented for C25 occurred in a single month in 2007. Dates are not shown in the data due to the VA research confidentiality requirement, that veteran's date deceased can be no more specific than year of death. C25 came to the VAMC for surgery related to colon cancer and remained at the medical center until he passed away.

The veteran's relational autonomous wishes were determined and confirmed early in the month, as follows. The DNR specificity helped clarify care agendas for veteran's care and

included on care that should not be provided. Formal caregivers efforts towards congruence and collaboration were implied, with “measures discussed at length” with family members.

Local Title: DNR - DO NOT RESUSCITATE

DO NOT RESUSCITATE: no resuscitation measures whatsoever should be taken for C25. Additional Information: Family discussion with Mr. Pxxx POA, and his wife, along with myself and Dr. Gxxx. Resuscitative measures discussed at length. Family is confident that patient would not want extraordinary measures taken for resuscitation, including: No Chest compressions, no shocks, no emergency cardiac medications. The patient will not undergo a CODE (*the aggressive measures of full code to sustain life at all costs*). The use of pressors (*agent that causes narrowing of an opening of a blood vessel*) to maintain blood pressure remains a possibility. We will be in contact with the family if the need arises. Signed by: MD, Surgery Resident

This was a case where spiritual needs were addressed and documented.

LOCAL TITLE: CHAPLAIN SERVICE CONSULT

Consulted with C25 normal concerns, expressed need for prayer and prayer was provided prayer and spiritual support. Ministered to family. Signed: Chaplain

LOCAL TITLE: MUSIC THERAPY CONSULT

Will provide bedside cognitive/sensory stimulation. Family said he liked gospel music. Have provided two 15 minute sessions; C25 responded favorably toward music stimulation. He appeared to recognize a few hymns and mouthed a few of the words to Amazing Grace. Will follow C25 1-2x per week, or more, time permitting. Thank you.

Signed: MT, Music Therapist

The following ethics referral entry indicated a reevaluation of the care agenda as family members advocated for continued care for their loved one. In spite of the specificity of the DNR order previously documented, case circumstances, related agendas and advocacy are all dynamic factors and can change quickly and dramatically as cases progress.

LOCAL TITLE: ETHICS REFERRAL

Disciplines Present: Attending, Nursing, Social Work, Chaplain

Reason for Referral: Dr. Rxxx requested a review of C25's current physical condition which has included futile care for the past four months at the VAMC following surgery.

Dr. Rxxx has spoke with patient's son and explained C25's condition. Dr. Rxxx requested the team review this case and make a recommendation to the treatment team and meet with the family if needed.

And, an ethics team follow-up meeting a few days later pointed to the need for continued communication with the family to include a team meeting with family members. Issues noted serious medical conditions and recommendation of comfort care only with no care escalation.

LOCAL TITLE: ETHICS TEAM FOLLOW-UP

Disciplines present: Nurse Practitioner, Nursing, Social Work, Chaplain, Dr. Chief of Surgery, Chaplain, LCSW, CNS, ,RN, , RN, , RN (ICU attending nurse). Issues:

1. cannot control pain for procedures
2. no benefit for treatment
3. fistula (*abnormal hole or connection between organs*) continues to grow
4. positive cultures (*infections*) - bacterium found

Team Recommendations:

1. family meeting with treatment team
2. withdrawal of care - comfort measures only
3. no escalation of care at this point
4. stay the course

Signed: Chaplain

The following segments of the final discharge summary reviewed the case and noted family involvement to the very end of life. This Korean War veteran passed away in the middle of the night with family at his bedside. Agendas and advocacy changed over the course of the month with psychosocial elements involved. The affective issues of losing a father and father-in-law, as well as relational elements in communication between a nearby son and his wife with a geographically more distant brother, may have led to a short period where care provided was not congruent with veteran's relational autonomous wishes. The DNR orders documented early in the month were later renegotiated to provide additional care, while VAMC professional caregivers had thought care had been futile, and likely too aggressive, for some time.

LOCAL TITLE: Discharge Summary

C25 had a very long and complex course, with multiple complications. He required massive resuscitation at the time of surgery. By June 17, he had complete renal shutdown. He continued to have problems, with acidosis and renal failure and sepsis. So he returned again to the OR to look for a cause. After that his renal function never

returned. He had several bouts of pneumonia and bacteremia/fungemia (*usually infection around a tube or catheter inserted in the body*). His lines were changed several times, and he had multiple courses of antibiotics. His mental status never really returned to baseline. There were several discussions with family about ongoing resuscitation. The terminal event was the appearance of hematuria (*presence of red blood cells in the urine*), which led to multiple transfusions and eventually cystoscopy (*bladder scope test*) to look for a source. After several investigations, it was realized that the patient likely had an enterovesical fistula (*abnormal hole formed between segment of bowel and the bladder*), which was resulting in recurring infections. Because the patient was too ill to undergo the major surgery, it was discussed with the family that we were only prolonging the dying of the patient. He was made Comfort Measures Only.

As noted by the resident: C25 died at 2:37am. Patient had episode of asystole (*no cardiac electrical activity*) at 2:26 am and had period of agonal beats (*very low heartbeat rate, 10-20 beats per minute*) followed by asystole again at 2:37. C25's son and daughter-in-law were at bedside. The heart monitor and ventilator were turned off. His medications and IVs were turned off. Time of death was 2:37am. Signed, MD, Chief of Surgery

The four stages of analyses presented above led to the theoretical storyline of formal and informal caregivers negotiating and advocating for agendas that were as congruent as possible with veteran's relational autonomous values and care preferences.

Study two substantive theory was, agendas advocating for relational autonomy. Theory development was demonstrated in case analyses. Now, the theory will be visually represented in the Relational Ethics model. The full model (see chapter 6, pages 171-177) contains four quadrants representing agency, agenda, advocacy, and resultant relational autonomy.

Relational Ethics – Dynamic Dimensions Model

Figures 4 and 5 on pages 162 and 163 respectively, display one quadrant, for the core category of relational autonomy, of an integrative, dynamic-dimensions model of relational ethics presented in full in chapter six. The relational autonomy quadrant was selected, since it is the culmination of the dynamics of participants' agendas and advocacy in study two; in the complete model, their agency is included as well. The full model is circular and the relational autonomy quadrant is the top right quadrant, the veteran patient is at the center.

Each quadrant of the Relational Ethics model can also be conceptualized as three-by-three matrix, with one side representing dimensional strength (weak, moderate, or strong) and the other side congruence, as indicated in three zones (less, moderate, or more), and referenced to the veteran’s relational, principled, relationally autonomous, care preferences. Study two dimensional matrix for agenda, advocacy, and relational autonomy:

| | | |
|--|---|---|
| Dimensional Strength Strong Less Congruent Zone | Dimensional Strength Moderate Less Congruent Zone | Dimensional Strength Weak Less Congruent Zone |
| Dimensional Strength Strong Moderately Congruent Zone | Dimensional Strength Moderate Moderately Congruent Zone | Dimensional Strength Weak Moderately Congruent Zone |
| Dimensional Strength Strong (DESIRED QUADRANT) More Congruent Zone | Dimensional Strength Moderate More Congruent Zone | Dimensional Strength Weak More Congruent Zone |

The model uses three separate icons to represent formal caregivers (F), informal caregivers (I), and veterans (V). The icons are shown in Figure 4 and 10 figure keys and are used to present the quadrant location of veterans, formal caregivers, and informal caregivers in reference to their strength and congruence on the dimension of relational autonomy. The position of the veteran’s icon in the quadrant demonstrates the culmination of all that has gone before in this research. The model thereby provides a snapshot view of case dynamics. As indicated by the model name and explained in study two analyses, the picture is seldom static.

The relational autonomy quadrant shown is a template for similar quadrants for the core axial categories of agenda and advocacy. However, the relational autonomy quadrant is unique, since it displays the culmination of the dynamics of the other quadrants. In this study, the

strength and congruence of agenda and advocacy of case participants determines the location of the veteran's icon in the relational autonomy quadrant. If agenda and advocacy are moderate in both strength and congruence, then the resultant autonomy will be moderate in strength and congruence; if those factors are weaker and less congruent, the resulting relational autonomy icon placements for participants will be weaker and less congruent as well.

The positioning of the three icons, representing the veteran and caregivers, displays the dimensional nature of the core category, relational autonomy. Quadrants for agenda and advocacy would place icons according to their, more or less, relative congruence with the veteran's care preferences and the relative strength of their agendas and advocacy. Note that caregiver's agendas and advocacy could be strong in their respective quadrants, but in the less congruent zone. The result, in the relational autonomy quadrant, would be the placement of caregiver icons as weak and less congruence.

For example C24 (Mobility Care), presented on pages 151-155, was a case where the veteran exercised in relational autonomy. Early in the case the helmet icon would have moved up the vertical axis into the less congruent zone and remained close to the vertical axis, since the level of relational autonomy was weak. As family got involved, their efforts combined with VAMC caregivers, moved caregivers to the more congruent zone and closer to the horizontal axis. In fact, collaborative efforts of formal and informal caregivers moved all icons towards more congruence and stronger appropriate (ethical, relational, principled) autonomy; an outcome that held for several years to come.

Referring to figures nine and ten respectively, the model reflects the significant differences between two cases, C2 and C9. Earlier in the research process these two cases were explored as part of the pilot study presented in chapter three, pages 53-71. C2 presented dynamics of significant incongruence, with the son wanting his father kept alive, regardless of indications that his father did not want such care and VAMC caregivers considering it inhumane. In contrast, C9 represented a nearly ideal case in terms of relational autonomy, with caregivers reaching congruence with one another's decisions, aligned with veterans care preferences.

C2's son had moderate to strong inrelational autonomy, therefore weak relational autonomy. He held Power of Attorney and, as of the ECRD, claimed to be the only family decision maker available. Later documentation and the appearance of a second son, proved otherwise. Therefore, as of the ECRD, the family icon, representing informal caregivers, showed

weak relational autonomy and less congruence with veteran's care wishes. Formal caregivers for C2 were moderately congruent in advocating for their understanding of the veteran's care preferences considering quality of life issues, but relatively weak in autonomy related to veteran's care, given that the son had legal authority and adamantly demanded full code care.

In C9 all caregivers, formal and informal, were congruent with the veteran's relational autonomous care preferences. As of the ECRD all participants showed strong relational autonomy, given their competence and alignment with veteran's care preferences. Therefore, all the icons are placed in the strong sector of autonomy and in a more congruent zone adjacent to the veteran patient.

Figures 4 and 5 present the relational autonomy quadrant for C2 and C9.

Relational Ethics

Dynamic Dimensions Model
(Relational Autonomy Quadrant)

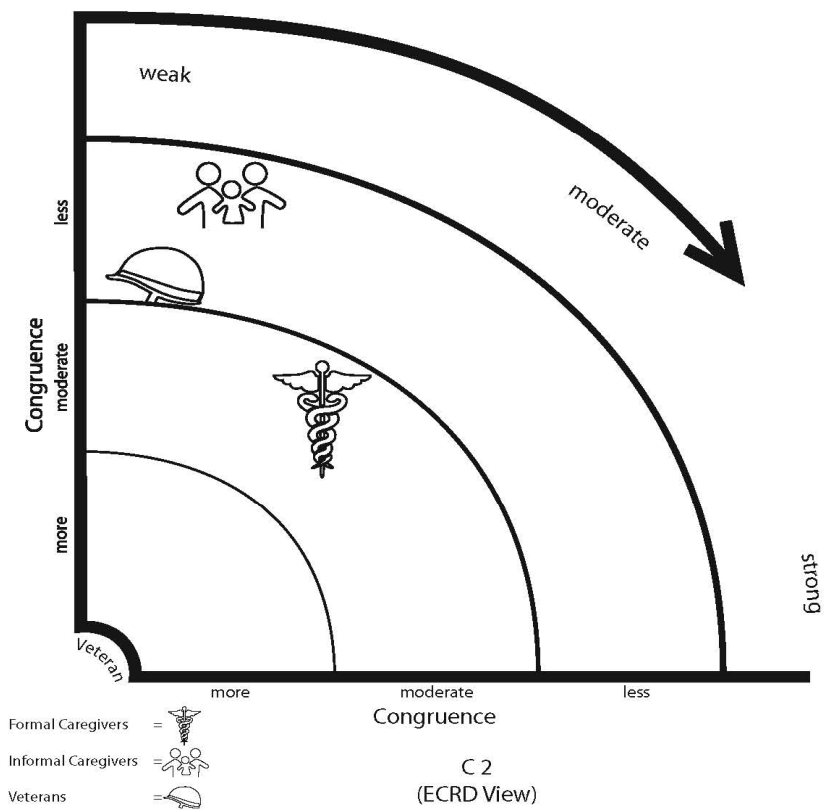


Figure 4. Relational Ethics Model – C2 Relational Autonomy Quadrant
(C2, as of ethics committee referral date, ECRD)

Relational Ethics

Dynamic Dimensions Model
(Relational Autonomy Quadrant)

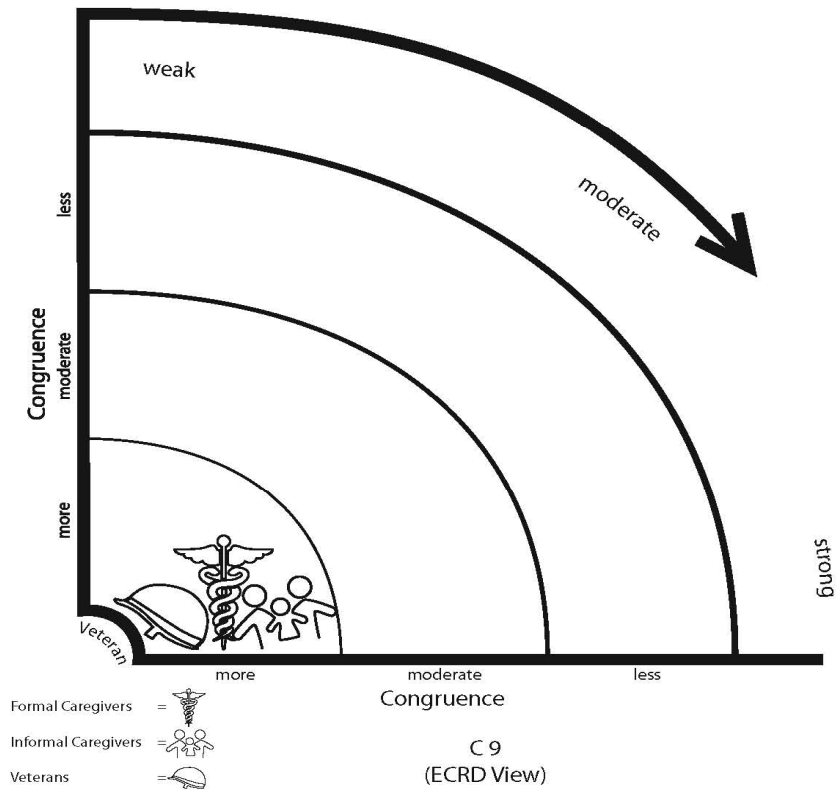


Figure 5. Relational Ethics Model – C9 Relational Autonomy Quadrant
(C9, as of ethics committee referral date, ECRD)

Concluding Remarks

As the curtain closed on Act II of our veterans' care dramas we understood that individual autonomy was seldom a realistic option. Our veterans were interdependently woven into a web of relationships that sought to support and promote their principled, relational, relational autonomy. Formal and informal caregiving actors were not always in agreement, but acted out their roles as they best understood them. Sometimes scripts, i.e. agendas, differed. Advocacy was sometimes reasonable, sometimes adamant and emotional. However, the agendas of advocate actors stayed focused on the veteran's mental capacity, physical condition, and caregiving in each case drama. The question of whether or not the person of the veteran remained the central character will be addressed in the final chapter.

In chapter six, following presentation of the full Relational Ethics – Dynamic Dimensions model, four cases from study two (C7, C12, C14, and C23), and four cases from study one (C18, C19, C20, and C21) will be reviewed from the complete model's substantive theoretical perspective. The research strategy, to choose exemplary cases for in-depth analysis, meant that these eight cases did not receive much attention in writing up and reporting on the two main studies.

In addition, the full Relational Ethics – Dynamic Dimensions model will be used to review pilot study cases C2 and C9.

CHAPTER 6 – CONCLUSIONS

This exploration of relational ethics in caregiving took nearly a year to complete. During that time the veterans and caregivers represented in the 25 cases acted as constant mentors. Their documented stories informed the development of two substantive theories, an integrated theory and model of relational ethics, and the following conclusions.

General Research Observations

First, this research confirmed effective ethical dilemma resolution by the VAMC ethics committee. Their recommendations were consistently congruent with the veteran's values and care preferences. In cases where the veteran lost capacity, the committee acted as veteran's agents and advocates. When informal caregivers were not involved, committee members recommended, or sought, identification of familial agents to help clarify and affirm veteran's preferences. Research results described dilemma resolutions that ultimately led to veteran's experiencing strong relational autonomy, congruent with their care wishes.

Biopsychosocial perspectives. By early April, after a few weeks of exploring the CPRS data, it became clear that finding relational and social information was going to take a lot of effort. The majority of the documentation was either quantitative or purely bio-medical in nature.

As mentioned in chapter one, the symbolic and actual differentiation of biological, psychological, and social entries in the documentation helped to deemphasize medical-biological data and focus on psychosocial entries (Frankel, Quill, & McDaniel, 2003). One of the first and most obvious research observations was the predominance of biological data. Psychological data was a distant second and social data was far behind the other two.

As presented in the pilot study (chapter 3, page 53), only 4 of the 10 data tab sections of the CPRS contained any significant amount of psychosocial data. After reviewing thousands of documents in those four data tab sections, it became clear that only about one in 10 held meaningful psychosocial information, and that was predominantly psychological. Making a very rough estimate of one-tenth of four-tenths of the data explored would be about 4% of the data. However, of the documents included in the study a large percentage of the content, conservatively 75%, excepting ethics committee and psychological consult entries, was focused on and recorded biological information. Roughly one percent of the data, split between psychological and social, and weighted more towards psychological aspects, represented a

realistic estimate of the amount of data meaningful to this research. One way this researcher reflected on this reality follows.

Current Situation: **BIO** Psycho social

Possible Alternatives: bio psycho social
Psycho social bio
SOCIAL Bio Psycho

Much of this bias towards medical-biological documentation made sense, given the context of a VA Medical Center. Certainly inpatient data should have included a preponderance of biological data. The biopsychosocial construct was initially suggested by a practicing physician (Engel, 1977). The original impetus for his new model was that the biomedical model in place at the time was insufficient. Engel argued that larger systemic contexts and social factors needed to be taken into account. Differing disciplines would likely place their perspective in the forefront as well. However, the dearth of social information in this research had significant consequences. Case 2 in the pilot study was a troubling example where a confused pronoun reference and lack of tracking family history and social data may have led to unethically prolonged life-sustaining care. In other cases (C3, C6, C14, C21, etc.) the lack of social information made finding guardians, or significant other agents to represent the veteran.

The implications for answering the main and study specific research questions were that the data addressing these questions was social and psychosocial in nature. The predominance of biological data meant that addressing research questions required more intentional and extensive exploration into CPRS case documentation. Relational ethics, as defined in chapter one page 2, emphasized relational and social interaction factors. Relational ethics substantive theory had to be grounded in data that presented social and psychosocial insights.

Missing strengths. As study one was coming to a close, there was awareness of a glaring oversight in the case files. Documentation of veteran's strengths was nearly non-existent. Agency emerged as the core category in study one and highlighted the importance of veteran's strengths and capacities to act as agents on their own behalf. The acknowledgement and validation of veteran's strengths and resources are a necessary, if not sufficient, part of the potential to actualize that agency.

There was one entry that said a veteran was “a survivor of the Battle of the Bulge,” one of the bloodiest battles of World War II. And, another statement that a veteran had received the Purple Heart, a military decoration awarded to those wounded or killed in action. In nearly 300 hours spent scanning thousands of CPRS case documents, those were the only two strength indicators noted.

The lack of documentation indicating veteran’s strengths troubled this researcher. This concern may have been biased by training and practice as a Marriage and Family Therapist (MFT). Identifying persons’ strengths, and documenting them in treatment plans, was an essential and standard procedure as a MFT.

Identifying and documenting strengths would only require a few lines of data. It was ironic that veterans, often described as our nation’s heroes, were not noted to have strengths and resources that may have supported their recovery. Thanks to an invitation by Dr. Kim to attend an ethics committee meeting in May 2008, I was able to visit another veteran’s bedside. The veteran was not part of the research population. However, that visit led to the following memo and enhanced awareness of the strengths oversight.

Visited the bedside of Mr. X today after attending a meeting of the ethics committee. Again, the two doctors present did more listening than speaking. This time a senior nurse with many years of experience made several specific suggestions accepted by all committee participants. Then we visited the veteran's bedside. Dr. Kim engaged the man immediately and asked about his military experience. Mr. X shared that he had survived frontline action in WWII and the Korea War. Later he said that he gets ornery with the VA staff because he wants more time at home (on weekends) rather than staying full time in the hospital. He said he does get irritated and tough to deal with sometimes.

I suggested that his toughness may have helped him survive two wars. He responded almost immediately saying, "Maybe, but I'm not going to survive this one. I know I'm not going to get well, but I can get better." He clearly understood his circumstance. Later that evening I had thoughts of Mr. X being Missing In Action (MIA). I thought of the importance of the survival of the self/person/identity along with the survival of the body.

Our strengths reside in our personhood and relationships. If a veteran’s strengths are not recognized or validated, how can their sense of self and self efficacy be maintained? A brief

paragraph that documented veterans' strengths, non-financial resources, interests, and "things you should know about me," could remind caregivers of veterans' personhood, strengths and uniqueness as human beings.

Integration of Substantive Theories

Research memos were folded into the analytic narrative during main study one and two analyses. Memo writing continued throughout the research process, guiding concept formation, category linking, and theory building. In this chapter several research memos were used to explain general observations and substantive theory integration.

By the time the curtain had come down on our series of two-act, veteran caregiving plays, the two substantive theories had begun to merge. The resulting combination was the dynamic process of clarifying agency with the agenda to advocate for relational autonomy. Samples of research memos, that trace reflections towards combining the two theories, follow.

6/7/08 Memo: Thoughts of the word agency to operationalize the desired directions of care and dilemma resolution. Ironically those more collaborative and connected to others, in a sense less independent, and more relationally engaged, have better chance of having someone emerge as an agent if veteran loses agency. That agent can become an advocate for vet who loses agency.

6/25/08 Memo: This morning thought that the most salient relationships in this process appear to be agentic relationships. Martin, Sugarman, and Thompson (2003) "Psychology and the Question of Agency is right on target. See page 44 and others. They bring in Bandura as well. There may be definitions of each key term from each biopsychosocial perspective? That would accentuate the SSSI nature of definition/meaning making by pointing out similarities and differences from those three perspectives.

8/1/08 Memo: Mackenzie and Stoljar (2000) *Relational Autonomy* is an edited book that presents what could easily be framed as "shared autonomy" to use Dr. Kim's words; autonomy that extends beyond the self, as all autonomy does, from an SSSI perspective. All the pieces do seem to be coming together around SSSI and the interactive dynamics between the individual and society which in its simplest terms is roles and relationships transacted with other people. For me as an MFT and from my life experience; it's all about relationships...

8/27/08 Memo: Thoughts about autonomy, agency and agendas. The issue of autonomy seems core to many case dilemmas. But autonomy requires some level of agency to make any difference in care trajectory. Agency - the condition of being in action; operation; and, a means or mode of acting; instrumentality. The noun agent as one that acts or has the power or authority to act. AGENT EMPHASIZES DOING (remember do-be-have). Further, instrumentality - the state or quality of being instrumental. And, instrumental - serving as a means or agency. All this implies that something gets done and an agent or perhaps shared agency gets it done. So, agency should have the agenda to promote and extend autonomy for as long as feasible.

There were other memos and notes but the trajectory towards combining the two theories is apparent. Once the two substantive theories were language linked, visual modeling began with many versions being incomplete or confusing. Finally, the version partially presented in chapter five and now shown in complete form, came together as shown in Figure 6, page 171.

Relational Ethics – Dynamic Dimensions Model

The relational ethics model presented in Figure 6 consisted of five interacting dimensions, agency, agenda, advocacy, relational autonomy, and congruence. All terms except congruence, which was explained in chapter five and this chapter, were defined in chapter one, table one, page 14. Once the two substantive theories were integrated and represented in a visual format it became clear that dimensional definitions were also relational, in that each dimension could be defined in terms of the others. Autonomy could be defined as the identification and exercise of agency following a specified agenda, conveyed or advocated to others in speech or writing; agency as the ability to act on agendas that advocated for relational, principled, relational autonomy, and so on.

The dynamic dimensions model was non-linear. Dimensions of agency, agenda, advocacy, congruence, and differing degrees of relational autonomy were randomly noted throughout case documentation. Documented indications of who had the power to decide and act, whether their agenda was documented or otherwise clearly expressed, how agentic messages were delivered or advocated for, how much or little such efforts were aligned with veteran's care preferences, and whether veteran's experienced level of autonomy seemed appropriate, were often co-occurring phenomena.

As explained in chapter 5, page 159, each quadrant in the model can be conceptualized as a three-by-three matrix of dimensional strengths. Agency, agenda, advocacy, and relational autonomy are judged to be dimensionally weak, moderate, or strong. Dimensional strength is indicated by clockwise movement from weak to moderate to strong. The other side of the matrix represents the congruence dimension. The level of congruence is indicated in three zones (less, moderate, or more congruent) as referenced to the veteran's relational, principled, relational autonomous care preferences.

The model uses three different icons to represent formal caregivers, informal caregivers, and veterans. The icons are shown in the Figure 6 key and are used to present the quadrant location of veterans, formal caregivers, and informal caregivers in reference to their respective dimensional strength and zone of congruence.

As explained in Chapter five, of the four quadrants in the model, the relational autonomy quadrant is unique. It displays the culmination of the dynamics of the other quadrants, agency, agenda and advocacy. If these dimensions are moderate and less congruent then the resultant autonomy will be moderate and less congruent as well. The underlying theme of congruence is the glue holding the model together, congruence between dimensions, and with veteran's appropriate care preferences. Questions of congruence permeate the model.

Most importantly, the positioning of the veteran's icon in the relational autonomy quadrant is the culmination of all that has gone before. In each veteran's case the dynamics of agency, agenda, and advocacy, along with their relative congruence with veteran's care preferences, culminates in the positioning of icons in the relational autonomy quadrant. Icon positions display the dynamics of relational autonomy at that point in time. It also provides a picture of delivered and experienced care that is either congruent or incongruent with veterans' preferences. Relationally ethical interactions should produce more congruent and strong autonomy in quadrant four. The model thereby provides a snapshot view of case dynamics that can change quickly, and dramatically.

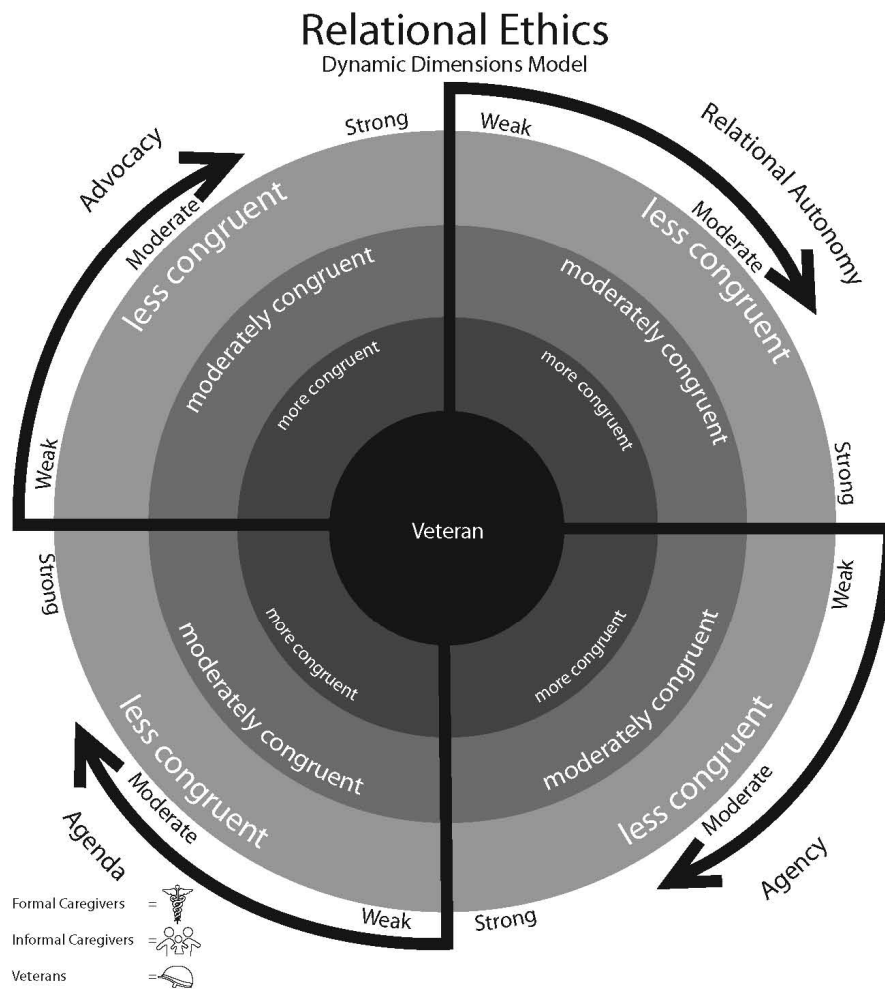


Figure 6. Relational Ethics Model – The Basic Model

In Figure 7 the positioning of the three icons in each of the four quadrants was represented by a single dot to indicate the likely unattainable, ideal situation. Each participant or participant group dimension was strong and perfectly congruent with one another, and with the appropriate care preferences of the veteran patient.

C9 (Home to Die) in Figure 8, using the model icons represented nearly that ideal condition, as of the ethics committee referral date. Although there were some relational processes required as part of the social structural context of the VAMC, all documentation indicated dimensional strength in terms of agency, agendas, advocacy and resulting relational autonomy; to spend five weeks at home with his loved ones before dying.

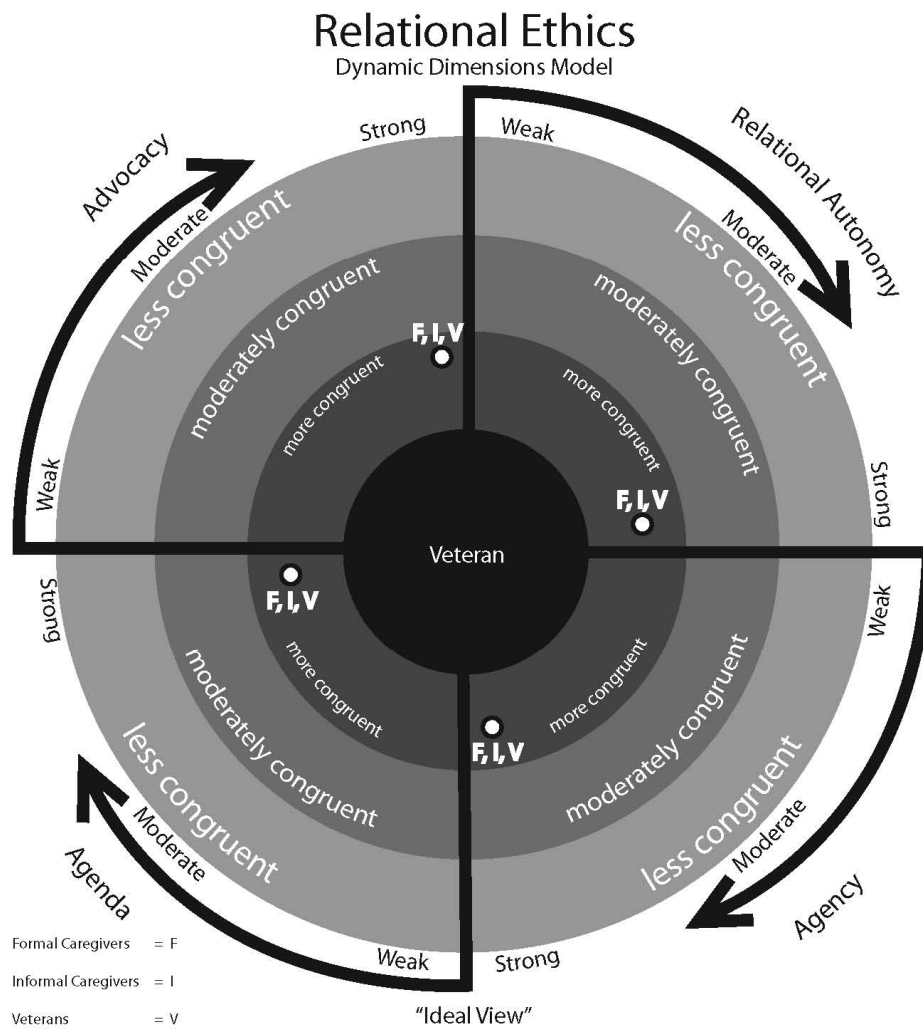


Figure 7. Relational Ethics Model – Ideal View

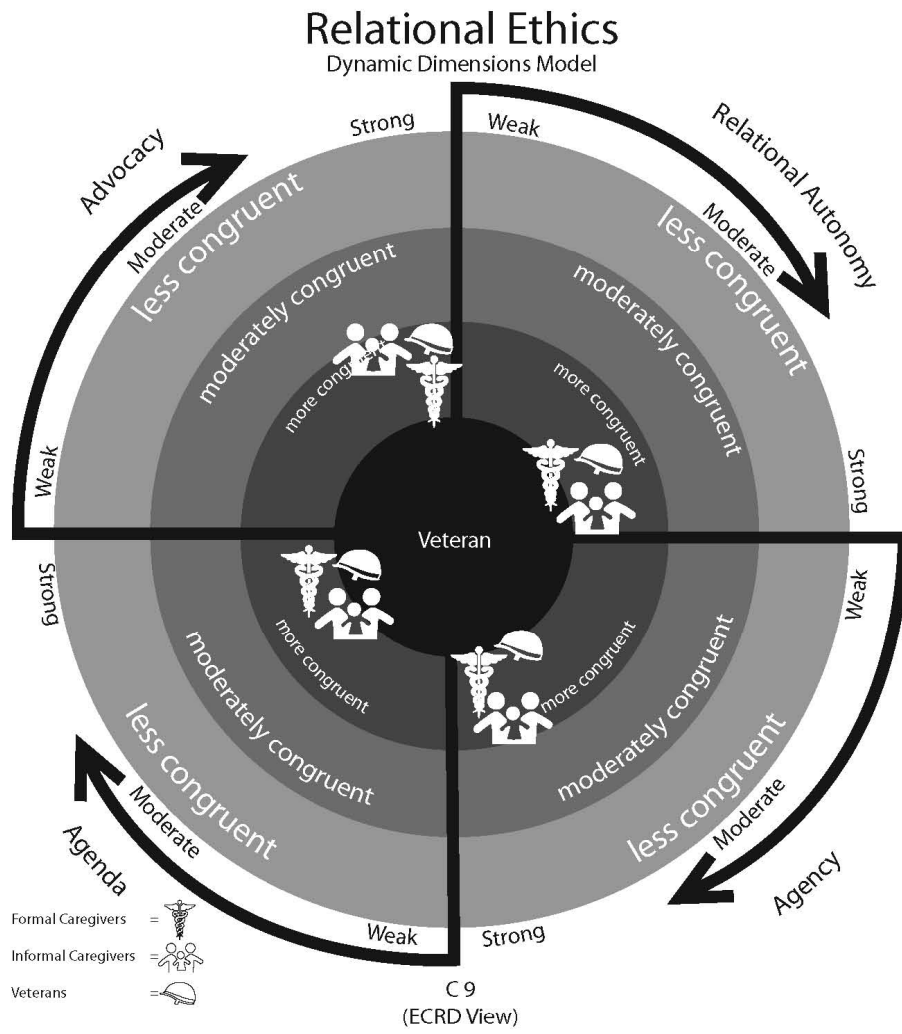


Figure 8. Relational Ethics Model – C9 ECRD View

In contrast, figures 9 and 10 present C2 (Lost Son), showing model dynamics pre and post ethics committee consult and recommendations. Note in Figure 9 that although the family icons indicate strength in agency, agenda, and advocacy, the indication in the relational autonomy quadrant is weak due to the presumed incongruence of those dimensions with veteran's care wishes. Since the veteran is in such a weakened condition, he is dependent on the agency of others to determine the degree of congruence between his circumstantial reality and desired relational autonomous condition; hence his icon's placement in the weak autonomy, less congruent position. The formal caregivers' agenda and advocacy icons indicate strength and more congruence. However, their agency is relatively weak and in the relational autonomy quadrant their icon is positioned as moderately congruent and relatively weak, due to the legal priority of the son's wishes for aggressive, full-code care.

Of course all such positioning of icons is subjective in nature. However, the model provides a way to visualize case circumstances and conceptualize strategies for moving dynamics towards more strength and congruence.

Figure 9 presents C2 after an ethics consult makes recommendations and another son living in a distant state becomes involved. There is a dramatic shift in the position of the veteran's icon in the relational autonomy quadrant. Recorded family history that had been overlooked for some time, clarified that the veteran would not want aggressive care. Notice that although the veteran's icon has not moved in the other three quadrants, the agentic actions of caregivers has shifted to more congruence with his preferences and moved his icon to a strong, more congruent position.

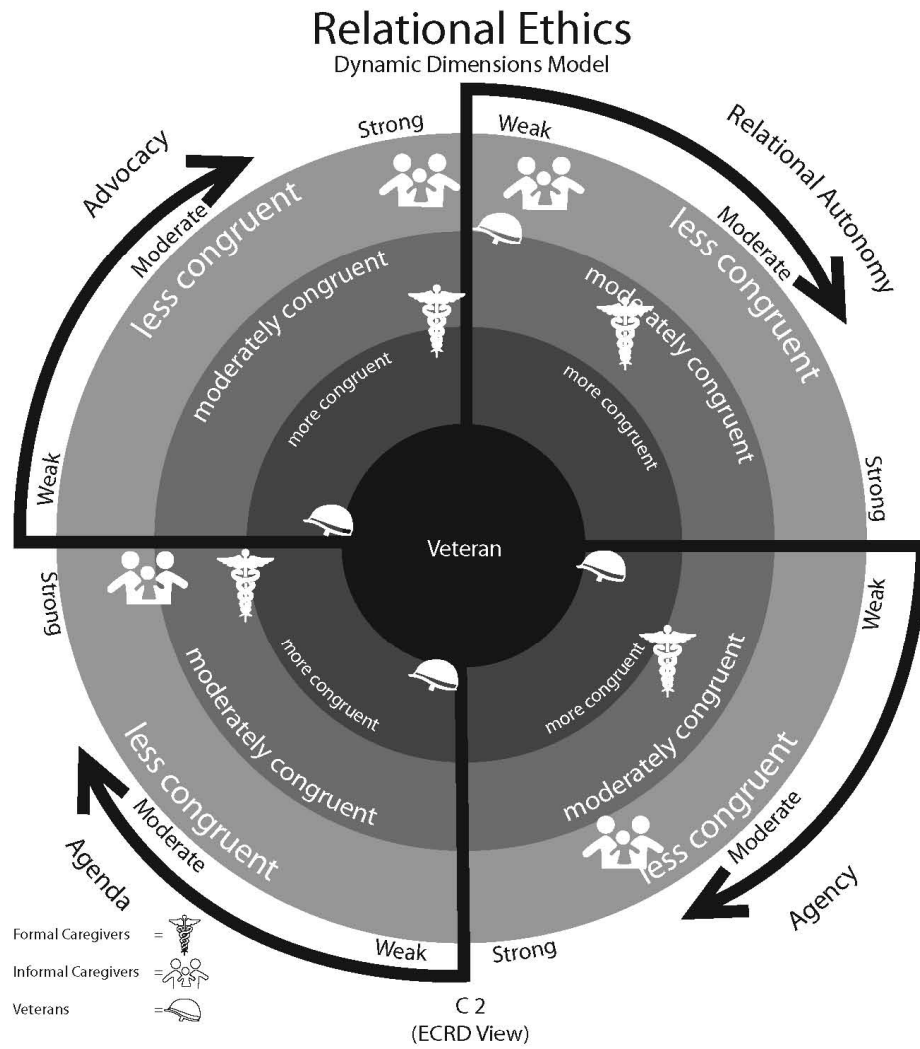


Figure 9. Relational Ethics Model – C2 ECRD View

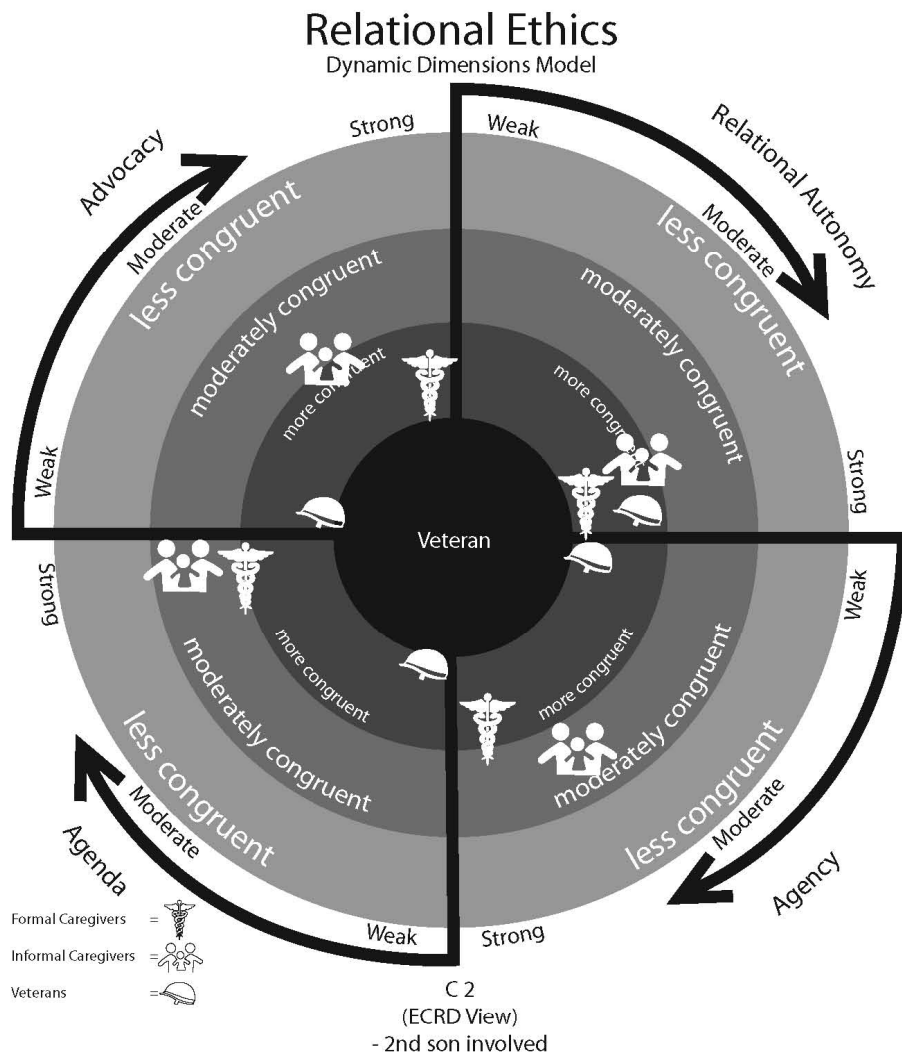


Figure 10. Relational Ethics Model – C2 Post-ECRD View

Application of the Full Relational Ethics Model

Eight cases from the research population, viewed around the time of the ethics committee referral and consult, will now be reviewed in brief. Case circumstances will be described from the perspective of the integrative model just presented.

Four cases from study one:

C18 (Only Pain) – a veteran sailor from the Korean War era

C19 (Comfort Only) – a veteran sailor from the post Korean War era

C20 (Blood Dangers) – a veteran sailor from the Vietnam era

C21 (Lost Family) – a veteran soldier from the post Vietnam era

Four cases from study two:

C7 (Pulled Tube) – a veteran airman from the Vietnam era

C12 (Family Agrees) – a veteran soldier from the Korean War era

C14 (Intensive Care) – a veteran soldier from the WWII era

C23 (Opposed to Surgery) – a veteran soldier from the WWII era

Case presentations, applying the combined substantive theory, the dynamic process of clarifying agency with the agenda to advocate for relational autonomy, will number the model quadrants in the sequence of the written theory. Agency will be quadrant one (Q1), agenda quadrant two (Q2), advocacy quadrant three (Q3), and the culmination quadrant of relational autonomy as number four (Q4). The participants are designated as F for formal caregivers, I for informal caregivers, and V for veteran patients. Case descriptions are paraphrased from CPRS documents; abbreviations for case presentations are:

Agency = Q1

Agenda = Q2

Advocacy = Q3

Relational Autonomy = Q4

Formal Caregivers = F

Informal Caregivers = I

Veterans Patients = V

Figures 11 through 14 present 3x3 matrices for each quadrant of the integrated relational ethics model; veterans, formal caregivers, and informal caregivers, identified by case number subscripts, are placed according to dimensional strength and congruence with veteran's relationally autonomous care preferences. Narrative explanation of analysis follows the matrices.

| | | |
|---|--|---|
| <p>Dimensional Strength Strong</p> <p>Less Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>V_{C23}</p> <p>Less Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>Less Congruent Zone</p> |
| <p>Dimensional Strength Strong</p> <p>F_{C12}, I_{C14}, F_{C14}</p> <p>Moderately Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>V_{C20}, F_{C23}, I_{C23},</p> <p>Moderately Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>I_{C20}, V_{C21}, V_{C7}, V_{C12}</p> <p>Moderately Congruent Zone</p> |
| <p>Dimensional Strength Strong</p> <p>F_{C18}, I_{C18}, F_{C19}, I_{C19}, F_{C20}, F_{C21}, F_{C7}, I_{C7}, I_{C12}, V_{C14}</p> <p>More Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>More Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>V_{C18}, V_{C19}</p> <p>More Congruent Zone</p> |

Figure 11. Quadrant One (Q1), Agency, Dimensional Matrix for 8 Cases

(Note. **F** = Formal Caregivers; **I** = Informal Caregivers; and **V** = Veteran Patients
Subscripts indicate case numbers, e.g. **V_{C18}** represents Case 18 veteran patient.)

| | | |
|---|--|--|
| <p>Dimensional Strength Strong</p> <p>Less Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>V_{C23}</p> <p>Less Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>Less Congruent Zone</p> |
| <p>Dimensional Strength Strong</p> <p>I_{C14}, F_{C14}</p> <p>Moderately Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>V_{C20}, F_{C23}, I_{C23},</p> <p>Moderately Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>I_{C20}, V_{C7}, V_{C12}</p> <p>Moderately Congruent Zone</p> |
| <p>Dimensional Strength Strong</p> <p>I_{C18}, F_{C19}, I_{C19}, F_{C20}, V_{C21}, F_{C21}, F_{C7}, I_{C7}, F_{C12}, I_{C12}, V_{C14}</p> <p>More Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>F_{C18}</p> <p>More Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>V_{C18}, V_{C19}</p> <p>More Congruent Zone</p> |

Figure 12. Quadrant Two (Q2), **Agenda**, Dimensional Matrix for 8 Cases

(Note. **F** = Formal Caregivers; **I** = Informal Caregivers; and **V** = Veteran Patients
Subscripts indicate case numbers, e.g. **V_{C18}** represents Case 18 veteran patient.)

| | | |
|---|--|--|
| <p>Dimensional Strength Strong</p> <p>Less Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>V_{C23}</p> <p>Less Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>Less Congruent Zone</p> |
| <p>Dimensional Strength Strong</p> <p>I_{C14}, F_{C14}</p> <p>Moderately Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>V_{C20}, F_{C23}, I_{C23},</p> <p>Moderately Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>I_{C20}, V_{C7}, V_{C12}</p> <p>Moderately Congruent Zone</p> |
| <p>Dimensional Strength Strong</p> <p>I_{C18}, F_{C19}, I_{C19}, F_{C20}, V_{C21}, F_{C21}, F_{C7}, I_{C7}, F_{C12}, I_{C12}, V_{C14}</p> <p>More Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>F_{C18}</p> <p>More Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>V_{C18}, V_{C19}</p> <p>More Congruent Zone</p> |

Figure 13. Quadrant Three (Q3), **Advocacy**, Dimensional Matrix for 8 Cases

(Note. **F** = Formal Caregivers; **I** = Informal Caregivers; and **V** = Veteran Patients
Subscripts indicate case numbers, e.g. **V_{C18}** represents Case 18 veteran patient.)

| | | |
|---|---|---|
| <p>Dimensional Strength Strong</p> <p>Less Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>Less Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>V_{C23}</p> <p>Less Congruent Zone</p> |
| <p>Dimensional Strength Strong</p> <p>F_{C23}, I_{C23}</p> <p>Moderately Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>I_{C14}, F_{C14}, I_{C20}</p> <p>Moderately Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>V_{C14}</p> <p>Moderately Congruent Zone</p> |
| <p>Dimensional Strength Strong</p> <p>F_{C18}, I_{C18}, V_{C18}, F_{C19}, I_{C19}, V_{C19}, F_{C20}, V_{C20}, F_{C21}, V_{C21}, F_{C7}, I_{C7}, V_{C7}, F_{C12}, I_{C12}, V_{C12}</p> <p>More Congruent Zone</p> | <p>Dimensional Strength Moderate</p> <p>More Congruent Zone</p> | <p>Dimensional Strength Weak</p> <p>More Congruent Zone</p> |

Figure 14. Quadrant Four (Q4), **Relational Autonomy**, Dimensional Matrix for 8 Cases

(Note. **F** = Formal Caregivers; **I** = Informal Caregivers; and **V** = Veteran Patients
Subscripts indicate case numbers, e.g. **V_{C18}** represents Case 18 veteran patient.)

Full relational ethics model analysis for study one cases. C18 was 75 years old when he was admitted to the VAMC for the last time. He subsequently developed respiratory failure and was intubated to protect his airway. Three weeks later C18 had a tracheotomy, a tube was placed directly into his windpipe. C18 showed no signs of recovery. He had a history of advanced dementia and a CVA, cerebrovascular accident, which usually involves death of brain cells due to lack of oxygen. The veteran was only responsive to pain, and nothing else. C18's Power of

Attorney had Alzheimer's dementia therefore decisions were being made by another next of kin (NOK), a brother in New York. Two sisters were involved through communication with C18's brother. The family decided to provide only comfort care. Palliative care and ethic consults were requested. Palliative caregivers recommended pain management with morphine, the ethics committee recommended coordinating care decisions with the brother and sisters.

Model analysis for C18 involved placement of icons in the quadrants. First, a sense of the veteran's relational autonomous wishes needed to be determined. The ethics committee rightly deferred to family members who are usually judged as best capable of knowing the veteran's wishes. In this case there were no advanced directive details to help. Since the family decided on comfort care only that is the presumed reference for subjective congruence icon placement.

In Q1, F and I were placed in the strong, more congruent zone. V was placed in the weak more congruent zone in Q1, Q2, and Q3, since in such a debilitated state there was little or no agency to advocate for any agenda incongruent with agents' decisions. In Q2 and Q3, F was moderate in agenda since they were deferring to family decisions makers. I was strong in Q2 and Q3. Both F and I were more congruent in Q2 and Q3. In Q4 F, I, and V were placed in the ideal area of more congruent and strong, since there was agreement on comfort care only as appropriate and presumed to meet what would have been the veteran's care preference if he could have spoken for himself.

C19 (Comfort Only) had incurable cancer determined by an oncologist who recommended supportive and comfort measures only. C19 suffered from delirium caused by multiple medical conditions and a chronic mental disorder. He was not engaged in conversation at all. His eyes were almost always fixed and he had no response to verbal stimuli and no grasp reflex. C19 had no capacity to make an informed decision as to his health care and general well-being. He also had no NOK at the time of the ethics referral. However, one of the VAMC doctors was able to contact C19's sister-in-law who was appointed as his Power of Attorney. The doctor stated that during a previous evaluation with C19, when he seemed to have the capacity to comprehend questions regarding care, he had expressed the desire for no heroics and comfort care only. Due to the veteran's poor QOL and chronic medical/mental conditions both the doctor and POA agreed that comfort care would have been C19's care preference. The ethics committee agreed with the recommendations of the medical team and POA and suggested there should be no artificial feedings or intubations of any kind. There is no evidence that they would prolong his

life and increase QOL. All agreed that considering the severity of C19's conditions, no active curative interventions should be attempted, especially any interventions that would cause discomfort. However, injectable medications were recommended by the committee for severe agitation associated with delirium to insure the safety of the patient and others.

Model analysis for C19, placement of icons in the quadrants: F and I were in the strong and more congruent position in Q1, Q2, and Q3, since there was agreement on proposed comfort care. V was placed in the weak more congruent zone in Q1, Q2, and Q3, since in such a debilitated state there was little or no agency to advocate for incongruent agendas and V was clearly without the ability to function on those dimensions. In Q4, F, I, and V were placed in the strong more congruent zone given their alignment with previously expressed care preferences.

C20 (Blood Dangers), had a complicated medical history of pancreatic cancer, hypertension, chronic back pain, and bipolar disorder. His wife and primary caregiver was dealing with her own significant health problems. C20 had a Whipple procedure (*A type of surgery used to treat pancreatic cancer*) performed at the VAMC, during which he received a blood transfusion. After the surgical procedure and transfusion the VAMC was notified by the American Red Cross that the blood donor had spent time in a vCJD area and the blood should be returned. A referral was made to the ethics committee for C20 by the Blood Usage Committee due to potential exposure to a variant of Creutzfeldt-Jakob disease (vCJD). vCJD is a very rare and incurable degenerative neurological disorder (brain disease) that is ultimately fatal. VAMC staff reviewed the literatures related to vCJD. Potential exposure to vCJD by blood transfusion was found to be only a theoretical possibility. The ethics committee noted, confirmed by staff reports, that C20 was surgically and psychiatrically stable and should be able to comprehend the situation related to his blood transfusion. There was no clinical evidence that disclosing the potential exposure to vCJD would potentially harm C20. The committee advised that a physician involved in his care should inform C20 of possible exposure and explain that the possibility of him contracting the disease was only theoretical and very unlikely.

Model analysis for C20, placement of icons in the quadrants: C20's case was unique in that the critical incident was in the past, blood transfusions cannot be undone. The focus of relational autonomy in this case was the ethics of honesty (being informed) versus deception (keeping the exposure hidden from C20). The incident of exposure to vCJD did not have to be shared with C20, but it was. I was weak in all quadrants since C20's wife was the only

documented family member and was involved in her own health struggles. The I icon was placed in the moderate congruence zone in all quadrants, since there was no information on her agreement or disagreement with informing her husband. In Q1, Q2, and Q3, V was placed in the moderate position for both dimensional strength and congruence since the documentation only alluded to his relative mental and physical ability to comprehend the situation. F was placed as dimensionally strong and more congruent in Q1, Q2, and Q3, based on the assumption that being informed would have been C20's relational autonomous preference. In Q4, I was in the moderate position for both dimension and congruence, while F and V were in the strong, more congruent position since the veteran was informed of what had happened.

C21 (Lost Family) had a mother and sister involved in his life about six years prior the caregiving circumstances described here. By the time of the ethics consult C21's mother had passed away and an exhaustive search to find his sister proved futile. He had lung cancer that had metastasized, spread, to other organs. C21 was unable to respond appropriately to verbal questioning, give consent, or make decisions. He was very weak and restless, but calmed when spoken to. He had a dramatic decline in cognitive and functional abilities. C21 was unable to care for himself and walk independently, so he was no longer appropriate to live in the Home for Adults where he had been for several years. He had been admitted to the VAMC Extended Care Rehabilitation Center (ECRC) for palliative care. The ethics team recommended honoring the veteran's living will by providing only comfort care.

Model analysis for C21, placement of icons in the quadrants: First, the I icon was not placed in the quadrants since no family was involved. In Q1, F was placed as strong and more congruent and V was placed as weak on agency and moderate on congruence. V was placed in the strong and more congruent zone in Q2 and Q3 due to the Living Will that described and advocated for C21's care wishes. F was also considered strong and more congruent in Q2 and Q3, due to alignment with veteran's wishes and VAMC staff's willingness to seek confirmation from the ethics committee on providing only comfort care. In Q4, F and V were placed as dimensionally strong and more congruent in honoring C21's care wishes.

Full relational ethics model analysis for study two cases. C7 (Pulled Tube), a 75-year-old veteran, was admitted to the VAMC for a massive CVA, or brain stroke. After his stroke, a feeding tube was placed due to difficulty swallowing. He was transferred to the VAMC's ECRC (Extended Care Rehabilitation Center). C7 pulled out his feeding tube despite sturdy wrappings.

His wife and daughter were involved and did not wish the tube re-inserted. The ethics committee provided a consult on request. They reviewed C7's advance directives in the CPRS. Strangely, it had all been crossed out. There was no way to know his care preferences through his medical records. C7 had no capacity to make informed decisions regarding his care and did not understand his medical condition. The ethics team saw no ethical problem in not re-inserting the feeding tube, per the wife and daughter's request, as long as the attending physician and family agreed. The advanced directives missing information was discussed with C7's wife. She said C7 did have a living will. Her decision for less aggressive DNR versus full code care was based upon prior advance directive discussion with her husband. Given dire medical conditions and poor prognosis request for DNR care was agreed on by VAMC doctors, nurses, ethics committee members and C7's family members.

Model analysis for C7, placement of icons in the quadrants: In Q1, Q2, and Q3, F and I were placed as strong and more congruent, since agents were actively involved advocating for agreed agenda of DNR care. In Q1, Q2, and Q3, V was placed as dimensionally weak and moderate in congruence since he could not directly express his wishes and was relying on formal and informal agents. In Q4, F, I, and V were in the more congruent strong position due to presumed alignment with veteran's care preferences.

C12 (Family Agrees) was admitted to the VAMC for wound management and care. He was taken to the Operating Room for incision and drainage of his left foot lesion. C12 tolerated the procedure well and was scheduled to return home shortly. However, he had increasing abdominal pain overnight, then severe respiratory distress and failure. C12 was transferred to the Surgical Intensive Care Unit where he was intubated (*tubes placed for feeding and breathing*) on arrival. He was stabilized in the Intensive Care Unit and maintained in critical condition for the next few days. C12 had a "do not intubate" order which was not known at the time of his acute emergency. VAMC staff decided to keep him intubated until he was totally weaned off of the ventilator. He was finally extubated (*tubes removed*) two weeks later. Tubes were removed after an extensive discussion with C12's sister, his power of attorney. She wanted ventilator support withdrawn. She believed that extubation and DNR orders were in keeping with the veteran's wishes, and confirmed by advance directives. C12 was extubated and initially did well off the ventilator. Comfort care was provided. C12's mental status and functioning declined over the next few days and he died not long after.

Model analysis for C12, placement of icons in the quadrants: In Q1, F was placed as strong and moderate in congruence due to intubation against a documented order of “do not intubate.” F was not placed as less congruent since caregivers were unaware of the order and began collaboration with family. F was more congruent and dimensionally strong in Q2 and Q3 in collaboration with family and following veteran’s care preferences in extubation and removal from ventilator. Due to respiratory failure V was placed as dimensionally weak in the moderate congruence zone in Q1, Q2, and Q3, since compromised mental and physical conditions weakened dimensional strength and made it difficult to assess issues of congruence with appropriate dimensional factors. I was placed as strong and more congruent in Q1, Q2, and Q3 since veteran’s sister had the agency, power of attorney, and advocated for a care agenda congruent with her brother’s wishes. In Q4, F, I, and V were all strong and more congruent, due to consensus to not intubate and provide non-aggressive comfort care.

C14 (Intensive Care) was an 86-year-old veteran admitted to the VAMC for congestive heart failure. He went into acute respiratory distress with fluid overload confirmed by chest x-ray. He was, therefore, intubated and transferred to the Intensive Care Unit (ICU). C14 remained on ventilator breathing support. Several meetings were held with his son and wife. They were made aware of what was going on and his overall prognosis. They initially wanted everything done. Later on they stated that even though they wanted everything done, they believed C14 would not wish to be on "life support" for an extended period of time. It was then agreed to try to optimize his medications and, after a certain time, he would be extubated (*taken off life support*). C14 was later extubated and transferred to a medical floor. His condition did not improve, in fact it deteriorated. He passed away early one afternoon; his wife and son were notified about his death over the phone.

Model analysis for C14, placement of icons in the quadrants: When the family was feeling ambivalent about level of care, I icons were placed as strong and moderately congruent in Q1, Q2, and Q3. Their ambivalence was understandable and VAMC staff collaborated with the family by maintaining life sustaining care while the family had time to come to the decision not to extend life support measures. F was placed as strong and only moderately congruent in Q1, Q2, and Q3, since the congruence reference is the veteran’s care preferences. V was placed as strong and more congruent in Q1, Q2, and Q3 since he had made advance directives stating a preference for less aggressive care. In Q4, V was placed as weak on dimensional strength and

moderately congruent since life sustaining care was in place, opposed to his wishes, while his family processed their feelings and care preferences for their loved one. F and I were placed as moderate in both dimensional strength and congruence during this time of family ambivalence.

C23 (Opposed to Surgery), was a 74 year old, 100 percent service-connected care veteran. He had schizophrenia and a cancerous mass on his right kidney, presumably a renal cell carcinoma. He was scheduled for surgery. He was opposed to surgery stating that the surgery had already been performed. It was difficult to determine, but seemed unlikely that the veteran understood his condition or had capacity to make a decision about surgery. C23's next-of-kin, his son, wanted him to have the surgery, though there may not have been complete consensus among all family members. Family members were unsure if they should go against C23's wishes and force him to have surgery. And, there was no court appointed guardian to decide. C23 had a long history of schizophrenia with hospitalization and placement in assisted living facilities. Even though C23's mother was deceased, he often believed she was waiting for him and he would wander around looking for her. He also struck his peers on several occasions, without provocation. The Ethics Committee dilemma was whether to honor the patient's stated wishes or support C23's family, as better able to decide on appropriate care. VAMC staff indicated that the patient's family was very involved. The consensus of the ethics team was to assist the family in making a decision as to whether or not the patient should have the recommended surgery. One son was the primary NOK and spokesperson for the family, but he wanted to involve his siblings in any decision where his father's life was at stake, like the surgery decision. All siblings were involved. The son spoke with his siblings and all were against a DNR care code for their father. C23 remained full code care for another 3 years, later given DNR code status in agreement with his family. He passed away not long after the removal of more aggressive care orders.

Model analysis for C23, placement of icons in the quadrants: In Q1, V was placed as dimensionally moderate in strength, but less congruent, since he was strongly opposed to surgery but not congruent with agency aligned with efforts to reach relational autonomy in Q4. In other words, his agency was not being used in the best interests of his own relational, principled, relational autonomy. V was placed as moderately strong in Q1 since caregivers in agreement could go against his wishes. V was placed as moderate in dimensional strength and less congruent with his own best interests in Q2 and Q3, since he was advocating for his agenda to go home and not have surgery. In Q1, Q2, and Q3, F and I were placed as moderate in both

dimensional strength and congruence since they were not aligned with veteran's preferences but taking those wishes into serious consideration and acting in what seemed his best interests. In Q4, V was placed as weak and less congruent since his expressed individual autonomous desires were not congruent with his relational autonomy, or best interests. In Q4, F and I were placed as strong in efforts to provide relational autonomy but not yet clear and aligned on care decisions; therefore only moderately congruent with veteran's care preferences.

This presentation was intended as a "test run" of the model. Icon positioning was subjective in all case analyses and argument could be made for other placements. The presentation of cases was meant to demonstrate how the model could be applied to any case and provide a means to describe and discuss case circumstances and desired care trajectories across disciplines and among any and all participants.

Brief Review of Qualities of a Good Substantive Theory

Of course, the quality of this research remains for others to decide. This researcher has little or no objective distance from the work. However, table 7 in chapter 3 acted as a guide, as recursive and reflective GTM processes developed substantive theory.

Therefore, in brief, the theory was grounded in the data as presented in numerous coded quotations, linked to code families, and concepts describing daily VAMC case realities. The categories developed had a range of properties with variability, similarities, and dimensions. The plausibility was verified by Dr. Kim; the researcher's limited time spent as a practicum student at the VAMC, and application of the individual substantive theories and integrated relational ethics theory to actual cases. The model offers an explanation of complex ethical dilemma resolution processes. Relational processes are clear but open to various interpretations regarding subjective dimensional strength in the integrated model.

The entire integrated relational ethics substantive theory can be stated in 13 words and, although somewhat intricate, the model presented complex processes in what was hoped to be an understandable format. It may have been possible to further delimit the integrated theory by parsing the concepts less finely, for example, perhaps agenda and advocacy could have been combined. However, the theory and model remained veteran focused and centered and provided one useful way to tell the story of institutional caregiving for veterans.

The theory is generative in that other recipients of services could be placed at the center of the model. Also, the need to promote a more appropriate versus individualistic autonomy has

ethical implications in numerous contexts, including family therapy, substance abuse counseling, and care for older persons in general. The theory is comprehensive in its conceptualization of elemental dimensions supporting relational autonomy and the recognition that these dimensions are dynamic and vary in dimensional strength.

The theory did seem to offer the potential to theorize about more formal, generic social issues as well. For example, if community were placed at the center of the model and posed as the focus of determining what would be an appropriate level of autonomy at that level, the implications of agency, agendas, and advocacy take on potentially different meanings and pose the importance of different relational interactions.

Limitations of the Research

There are notable limitations to this research. The Department of Veteran's Affairs runs 153 Medical Centers. This research explored 25 cases, at one of those Centers. VA Medical Centers serve only veterans and therefore qualitatively differ from medical facilities serving other populations and the general public. These facts may limit the explanatory potential of the developed substantive theories.

The use of CPRS documentation meant that the primary voice was formal caregivers. The voice of informal caregivers and veterans came through only as those making entries allowed. Record keeping and documentation by various disciplines carry their own potential biases and the temptation to slant the content to present oneself in the best light. Further, analysis of archived case documentation was several steps removed from the real life, day-to-day interactions between study participants. Only a couple of minor bedside observations were made and no face-to-face interviews were conducted; all analytical impressions were dependent on and limited to CPRS documentation.

The confidentiality requirement to remove all identifying information from the data meant the gender issues were not adequately addressed. Further, given that all the veterans in this study were male and the patient population at the VAMC was primarily male meant that caregiver-care recipient interactions were impacted by that reality. Caring for a predominantly male population by frontline, hands-on caregivers who were mostly female was not explored in this research. This gendered-environment issue did not present itself in the data in any recognizable way. However, there was little doubt that gender mattered in VAMC caregiving.

Race, age, and religious affiliation concerns were not addressed either. Except for the four black, African American veterans in the study, all the rest were non-Hispanic Caucasians. Therefore, the research did not adequately address the overall diversity of our veteran population. Forty percent of the research population was between the ages of 45 and 64, another 40 percent were 75 years old or older, and the remaining 20 percent were between 65 and 74 years old. The research did not analyze the data with these age differences in mind. There may have been significant age-difference factors impacting care processes that were not taken into account. Well over half of the research population was some denomination of the protestant religion, and several religious denominations were represented by a single veteran. Four of the 25 veterans were listed as religion unknown. There was no particular focus on analyzing the possible impact of religious belief on care, with the single exception of the veteran who was a Jehovah's Witness and requested no blood transfusions. These and other demographic factors may have been significant in ways that were left unexplored in both main studies.

The main study question regarding how relational ethics was reflected in resolution of ethical dilemmas was adequately addressed. However, many of the research questions specific to main study one and main study two were not answered. Questions of who requested consult, or initiated communication was seldom documented. One impression was that since visits were made to veterans' bedsides by medical treatment teams, the call for an ethics consult came from a collaborative decision. And, bedside visits produced entries by nurses that seldom gave specifics of the communication process. In most cases, no particular person was identified as initiating requests or interactions. Although the research explored how various disciplines participated, the removal of identifying information eliminated data necessary to answer which members were involved. Although role commitments were implied in formal and informal caregiver roles, the documentation did not directly answer questions regarding role commitment, salience, hierarchy, etc. The question regarding perceptions of relational ethics was only partially answered in the analysis of congruence of caregiver's agency, agendas, and advocacy with veteran's care values and preferences. Documented perspectives that could be identified as specifically addressing relational ethics were not apparent.

The substantive theories and integrated theory of relational ethics answered many questions regarding conceptual elements of the process and how it worked. However, the lack of face-to-face interviews or questionnaires addressing more specific study questions meant they

were mostly left unanswered. The significant question answered, that was not specifically asked, was what were the crucial factors and functions necessary to resolve ethical dilemmas in a manner that provided care to veteran's that was congruent with their appropriate care preferences.

The choice of caregiving relationships as the level of analysis meant that larger systemic influences were not addressed. SSSI theory reminded us that people were conscious of roles when acting in a social structural context. The VAMC presented a named and classified social structure that provided role expectations for professional disciplines and VA employees. Focus on documented caregiving relationships was not able to address higher level systemic issues impacting on the caregiving relationships researched.

Implications and Directions for Future Research

Future research implications and directions prompted by this research could begin with a broader exploration of caregiving congruence within health care facilities, beyond the VA system. Exploration of how well treatment plans align with patients' and various caregivers' preferences; the level of consensus between the various disciplines of formal caregivers; and between formal and informal caregivers, may discover conflicted agendas that impact the effectiveness of care. Application of the findings at higher systemic levels would question the congruence between mission statements, policies and procedures, professional healthcare discipline directives and ethical guidelines, and the day-to-day delivery of care services to care recipients. In other words, are official agendas congruent with the actions of identified and empowered agents?

Research within any of the proposed quadrants that attempted to quantify the three-by-three matrix dimensions of agency, agenda, and advocacy could conduct more sophisticated data analyses with larger samples to better test the validity of the proposed impact of dimensional strength on the outcome of relational autonomy. It would probably be most productive to begin with quantification of the relational autonomy quadrant because it is the proposed measure of actualized relational ethics in caregiving.

Additional research that placed other persons at the center of the model could provide useful information. For example, if a social worker, nurse, or doctor in their role as professional formal caregiver were placed in the center of the model, analyses of dimensional strength and congruence between agency, agenda, and advocacy would produce a very different and perhaps

useful conceptualization of ways to better support and empower important caregivers. If family were placed at the center yet another analytical picture could be produced. Such analysis could identify where agency is situated now, promote the agency of disenfranchised family members, clarify or uncover unstated agendas, and potentially create collaborative advocacy for appropriately increased autonomy for every member of the family.

Research could further clarify the dimensional measure and differentiation of agency and the agents who enact it, agendas as persuasive and potentially influential messages, and the effectiveness of advocacy in promoting agendas and messages, along with the resultant measure of relational autonomy, given the social context and larger resource issues at stake. Such clarification and measurement of dimensional factors could evaluate the functional effectiveness of individual or combined factors, applied in specific caregiving interventions and contexts.

Implications and Directions for Practice

Theoretical concepts from social structural symbolic interaction (SSSI), see pages 26 and 27 in chapter two, guided the research and helped explain the most significant research implication for practice. In brief, behavior was explained as dependent on a named and classified worldview, and people acted in social structural context conscious of role designations, role commitments, and social structural position. Stryker (1980) explained that the social person had no recognizable sociological position without reference to at least some elements of social organization and group.

The list of labels, diagnoses, and conditions was overpowering. To mention a few, physically veterans were named and classified as COPD (chronic obstructive pulmonary disease), CVA (cerebrovascular accident), hypertension, renal failure, bedbound, anemia, lethargy, etc.; mentally ill veterans were named and classified as depressed, bipolar, mildly demented, anxiety disorder, suicidal, delusional, and so on. Further, the designation of co-morbidity was often applied, meaning labels were attached in small bunches, often as combinations of both mental and physical classifications. For example, in the coded data, dementia was specifically documented 393 times and schizophrenia 283 times in the 25 cases.

Caregivers were named and labeled as licensed practical nurse (LPN), licensed clinical social worker (LCSW), attending physician, resident physician, psychiatrist, etc (all as M.D.s), Associate Professor of Clinical Psychiatry (MD), etc. Informal caregivers were designated as devoted wife, loyal son, resilient caregiver, long time girlfriend, and Power of Attorney.

In the documentation the veteran was most often referred to as patient, sometimes as the veteran, and occasionally by their proper name. Apart from these designations, the veteran as social person was seldom alluded to or described. The set of social structurally assigned meanings attached to the role of patient overwhelmed any sense of veteran as person.

The substantive theory in study one was the dynamic process of clarifying agency. This agency was meant to be exercised by veterans or, on behalf of veterans when they could not represent their own best interests. In study two, the agenda to advocate for relational autonomy was focused on the relationally embedded and principled autonomy of veteran, as social person in need of care. The integrative theory of relational ethics and dynamic dimensions model intentionally placed the person of the veteran at the center of all that transpires in every case.

The implication for practice is to keep the veteran as person central to all discussion, advocacy, all exercise of authority, agency, and all treatments plans and directives, agendas. Case documentation appeared to place the veteran's medical or mental condition at the center.

One data entry, discovered in the midst of study one analyses, was troubling. A physician, likely hurried and focused on solving medical problems, included the following entry as an item in their treatment plan.

Speak with dermal wound regarding any further skin care.

Signed, M.D., Medical Resident

(Dermal wound is defined as the loss of skin integrity; a skin opening or wound that may be superficial or deep). Obviously the physician meant to speak with the person about the wound, but the focus as documented was clearly on the condition not the veteran.

Recently a counselor and colleague shared the following anecdote. He recalled working part time in a VAMC in another part of the country just after leaving active military service. He helped process laboratory test results for veterans suffering from various lung conditions. He said, "It's been 20 years but I'll never forget what the doctor running the lab called those veterans. He said they were *Chronic Lungers* and there wasn't much hope for their future."

Another practice implication, more specifically related to ethical issues, raises a specific concern with language use. The term surrogate decision maker is commonly used in discussions surrounding ethical recommendations and decision making in healthcare. Apart from the legalistic nature of the term, the intentions of assigning a surrogate run counter to the implications of this research.

If the veteran is to remain the central focus of the caregiving process, patients do not need a replacement; they need a representative. There is ethical danger in the oversimplified assumption that patients either have the ability to be their own agentic advocates or they do not. In the cases reviewed in this research mental and physical capacity waxed and waned; and loss of capacity was more often a process, not an event. Clearly a point was reached in most cases where the supportive agency and advocacy of formal and informal caregivers was vitally important. However, caregiving participants consistently looked for indications that the veteran might still have some capacity to be part of deliberation and decision making processes. The practice implication is to leave the veteran at the center and focus attention on identifying agents with congruent agendas to advocate for patients best interests, not to replace them with a surrogate

Serious reflection on the theoretical concepts of SSSI related to role issues reinforced the importance of understanding veteran patients as social persons. Role identity, social position, and salience cannot be ignored or denied if relationally ethical care is to be consistently provided.

It is somewhat ironic that in order to act as ethical practitioners we should seek to work ourselves out of a job. Sooner or later, if caregiving relationships are functionally effective, care recipients grow beyond the need for our services; that held true in this research whether veterans recovered or not. If at every point in the caregiving process we can demonstrate that care recipient's relational autonomous care preferences are being honored; we can make a good argument that relational ethics are being exemplified. If, when veteran's capacity to act on their own behalf wanes, we can point to identified agents whose agendas advocate for the same appropriate level of autonomy, we have maintained our ethical stance.

Concluding Remarks

This presentation concludes with a brief return to my personal reflection, and the two bedside visits with C2, the combat veteran and once prisoner of war, and the tough, frontline, combat veteran who had survived two wars.

My memory of relationships with formal caregivers at Tachikawa Air Force base and Walter Reed hospital was being reprimanded for the lack of expected improvement in my hepatitis related blood counts. I suspect my drinking caused the problem. For those of us who were ambulatory, the depersonalization of not being allowed to wear our uniforms, with designations of rank, combat support group, etc, effectively erased our military identity. We were patients, nothing more.

I conducted three separate explorations of C2's (Lost Son) case, during the pilot study, then as part of each main study. I came away with the disturbing thought that the one veteran in the research population, who had been a prisoner of war, may have been a prisoner of the war between formal caregivers and death at the VAMC, for nearly a year. This war, or battle with death, was precipitated by the conflict between formal caregivers, who felt that aggressive care was inhumane, and the veteran's son, who lived nearby, refused to visit his father, yet had the legal power to insist on full-code, aggressive, care.

Finally, meeting with the veteran who knew that he was, "not going to survive this one" reaffirmed the importance of the veteran's personhood, or veteran patient as social person. We can only have ethical relationships with other persons, not with conditions or diseases. The veteran, as social person, needed to be preserved with the same diligence applied to preserving physical and mental health, including recognition of their strengths, values, and care preferences.

Substantive theories developed in this research explained that the dynamic process of clarifying agency, and agendas that advocated for relational autonomy, were first and foremost veteran centered. In social structural symbolic interaction terms the salience hierarchy of role identities placed the veteran, as social person, first. Next in the hierarchy, depending on case dynamics, came various formal and informal caregiver roles. Caregivers, especially VA ethics committee members in their roles as agents and advocates, supported ethical resolution of veteran patients' caregiving dilemmas. Each documented scene was, more or less veteran focused, depending on the congruence of enacted agency, agendas, and advocacy with veteran's relationally situated, principled, relationally autonomous, care preferences.

If the veteran's central position was compromised by becoming a labeled condition, or being replaced at the center by other persons or agendas, their personhood was at risk. The veteran, as social person, could go missing. Dramatic scenes portraying life saving techniques, heroic doctors and nurses, struggles over level of care near the end of life, dealing with immediate medical crises, and unacceptable veteran behaviors or intentions, were all capable of displacing the veteran person from their central position.

If the role salience of veteran as person was somehow lost, and not subsequently restored, there was a real danger of casting veterans in other, ethically unacceptable roles. Veteran actors could become missing in action (MIA) in our play. Or, as explained with veteran C2, be unintentionally cast in the implicit role of POW. Doing the right thing, by enacting relational

ethics in caregiving, can reduce, if not eliminate, the likelihood of veteran's roles taking on unacceptable characteristics of POWs or MIAs.

VAMC ethics committee members consistently enacted relational ethics, as agents advocating for veteran patients' personhood and relational autonomy. Substantive theory in this research described efforts to respectfully engage veterans and caregivers, maximize freedom of acceptable choice, acknowledge uncertainty and possibility, and provide a supportive environment for ethical deliberations.

The research raised concerns that VA documentation practices do not always prioritize concern for veteran patients as social persons. More importantly, we live in a dangerous world. We ask members of our society to voluntarily put their lives at risk to defend our nation. In time of war we ask them to support harming other human beings, sometimes at a terrible personal and social cost. George Washington stated, "The willingness with which our young people are likely to serve in any war, no matter how justified, shall be directly proportional to how they perceive veterans of early wars were treated and appreciated by our nation" (The American Legion Magazine, 2008, Cover Page).

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APPENDICES

Appendix A. Institutional Review Board Letter



Office of Research Compliance
Institutional Review Board
2000 Kraft Drive, Suite 2000 (0497)
Blacksburg, Virginia 24061
540/231-4991 Fax 540/231-0959
e-mail moored@vt.edu
www.irb.vt.edu

FWA00000572(expires 1/20/2010)
IRB # is IRB00000667

DATE: June 19, 2008

MEMORANDUM

TO: Jay A. Mancini
James Ford
Kye Kim

FROM: David M. Moore 

Approval date: 6/19/2008
Continuing Review Due Date: 6/4/2009
Expiration Date: 6/18/2009

SUBJECT: **IRB Expedited Approval:** "Influence of Relational Aspects in Ethics Consultative Practices: Microsystemic and Mesosystemic Studies", IRB # 08-372

This memo is regarding the above-mentioned protocol. The proposed research is eligible for expedited review according to the specifications authorized by 45 CFR 46.110 and 21 CFR 56.110. As Chair of the Virginia Tech Institutional Review Board, I have granted approval to the study for a period of 12 months, effective June 19, 2008.

As an investigator of human subjects, your responsibilities include the following:

1. Report promptly proposed changes in previously approved human subject research activities to the IRB, including changes to your study forms, procedures and investigators, regardless of how minor. The proposed changes must not be initiated without IRB review and approval, except where necessary to eliminate apparent immediate hazards to the subjects.
2. Report promptly to the IRB any injuries or other unanticipated or adverse events involving risks or harms to human research subjects or others.
3. Report promptly to the IRB of the study's closing (i.e., data collecting and data analysis complete at Virginia Tech). If the study is to continue past the expiration date (listed above), investigators must submit a request for continuing review prior to the continuing review due date (listed above). It is the researcher's responsibility to obtain re-approval from the IRB before the study's expiration date.
4. If re-approval is not obtained (unless the study has been reported to the IRB as closed) prior to the expiration date, all activities involving human subjects and data analysis must cease immediately, except where necessary to eliminate apparent immediate hazards to the subjects.

Important:

If you are conducting **federally funded non-exempt research**, please send the applicable OSP/grant proposal to the IRB office, once available. OSP funds may not be released until the IRB has compared and found consistent the proposal and related IRB application.

cc: File
Department Reviewer: Joyce A. Arditti

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Appendix B. VA IRB Approval and Waiver of Informed Consent Letter

Department of
Veterans Affairs

Memorandum

Date: April 15, 2008

From: Kye Y. Kim, M.D. (7-1)

Subj: Request for Waiver of Informed Consent for Study entitled: "Influence of Relational Aspects in Ethics Consultative Practices: Microsystemic and Mesosystemic Studies"

To: Chair, Human Studies Subcommittee (151)

This is a request for Waiver of Informed Consent because this research study conforms to the following four criteria:

1. The research involves no more than minimal risk to subjects (Consider physical, social, psychological and economical risk).
x Yes; justification: This study is based on a retrospective medical record review. There will be no additional risk to the subjects since their privacy will be kept per regulations.

No (If "no," a waiver of Informed Consent cannot be granted)

2. The waiver will not adversely affect the rights and welfare of the subjects.
x Yes; justification: This study is based on a retrospective medical record review. There will be no additional risk to the subjects since their privacy will be kept per regulations.

No (If "no," a waiver of Informed Consent cannot be granted)

3. The research could not practicably be carried out without the waiver.
x Yes; justification: This study is completely based on the existing data in the CPRS and will not interfere with patients' clinical care at all. There will be no additional risk to the subjects since their privacy will be kept for regulations.

No (If "no," a waiver of Informed Consent cannot be granted)

4. Whenever appropriate, the subjects will be provided with additional pertinent information after they have participated in the study.

Yes x No; justification: This study is based on a retrospective medical record review.



Principal Investigator

5-8-08
Date

Recommendation: Waiver of Informed Consent granted per 38 CFR 16.116 (d)

Waiver of Informed Consent NOT granted

Comments:



Chairman, HSSC

5/20/08
Date

2105
VA FORM
MAY 1995
Revised 11/2005

Appendix C. ALL CODES – 9/22/08

AD:DATE OF ADVANCE DIRECTIVE
AD:DISC W/VET W/O CAPACITY?
AD:DISCUSSED W/ VET
AD:DISCUSSED W/VET OR SURROGATE?
AD:DNR
AD:DNR RESCINDED
AD:DNR:CARE WITHHELD
AD:DNR:DETAILS
AD:DNR:DOC:RESIDENT
AD:DNR:DOC:STAFF PHYSICIAN
AD:DNR:GERPSYCH
AD:DPOA:MPOA:POA?
AD:FULL CODE
AD:GUARDIAN DESIGNATED?
AD:HONORED
AD:IN CHART
AD:LIVING WILL
AD:NO CHANGES
AD:NRS
AD:PHYSICIAN ASSISTANT
AD:STAFF PSYCHIATRIST
AD:SW
ADD:CHP
ADD:CONCURRENCE:DOC W/ DOC
ADD:DATE OF ADDENDUM
ADD:DOC: PRIMARY CARE
ADD:DOC:ATTENDING
ADD:DOC:INTERNAL MEDICINE
ADD:DOC:PROF OF NEUROLOGY
ADD:DOC:PSYCHIATRY RESIDENT
ADD:DOC:RESIDENT
ADD:DOC:STAFF PHYSICIAN
ADD:DOC:STAFF PSYCHIATRIST
ADD:GERIATRIC PSYCHIATRIST
ADD:NURSE ADDENDUM
ADD:SW
ADMISSION:DATE
ADMISSION:EVAL
ADMISSION:REASON
CARE:ADL's & IADL's
CARE:ASSISTED LIVING
CARE:COMFORT CARE ONLY
CARE:ECRC SCREEN?
DG:COMBAT VET OR NOT?
DG:DATE DECEASED
DG:DATE OF BIRTH
DG:DOC:PSYCHOLOGIST
DG:EDUCATION LEVEL
CARE:ECRC:EXTENDED CARE?
CARE:FAMILY
CARE:FOLLOW UP CARE
CARE:GOALS
CARE:HOME
CARE:INFORMAL
CARE:LEVEL CHANGE
CARE:LEVEL OF CARE
CARE:NURSING HOME
CARE:PLACEMENT
CARE:PLACEMENT:HOME
CARE:RECOMMENDATIONS
CARE:RESTRAINT & SECLUSION
CARE:REVERSIBLE DECISION
CARE:SPOUSAL
CARE:TOTAL CARE
CARE:TRANSFER
CARE:TX WITHHELD
CN:DATE OF CONSULT
CN:DOC:GERIATRICS
CN:DOC:NEUROLOGIST
CN:DOC:PROF OF CLINICAL NEUROLOGY
CN:DOC:PSYCHOLOGIST
CN:DOC:PSYCHRESIDENT
CN:DOC:RESPIRATORY
CN:DOC:RHEUMATOLOGY
CN:DOC:STAFF PHYSICIAN
CN:DOC:STAFF PSYCHIATRIST
CN:DOC:SURGEON
CN:ECRC SCREEN
CN:GPY:EOL ETHICS
CN:NRS:HOSPICE CARE
CN:NURS: HOSPICE
CN:NURS:COMMUN/HOME HEALTH
CN:NUTRITIONIST
CN:PHYS THER
CN:REASON FOR CONSULT
CN:SW
CONFLICT:DG STATE NEVER MARRIED
COUNSELING:HIV POST TEST
CPRS DOCUMENTATION REF
CPRS DOCUMENTATION:ERROR
DG:AGE
DG:ETHNICITY
DG:GENDER
DG:MARR STATUS
DG:MILITARY DECORATION
DG:NOK

DG:OCCUPATION
DG:POW OR NOT?
DG:RACE
DG:RELIGION
DG:SERVICE BRANCH
DG:SERVICE CONNECTED DISABILITIES
DG:SERVICE ERA
DISC:AMA(AGAINST MED ADVICE)
DISC:ASSESSMENT:PROGNOSIS
DISC:DISCHARGE
DISC:DISCHARGE PLAN
DISC:HOME
DISC:NO DISC SUMM FOR VET
DISC:NOTE:NRS
DISC:NRS:EOL
DISC:RECOMMENDATIONS
DISC:SUMM:DATE OF DISCHG SUMM
DISC:SUMM:DOC:ATTENDING
DISC:SUMM:DOC:CARDIOLOGIST
DISC:SUMM:DOC:HOSPITALIST
DISC:SUMM:DOC:PSYCHIATRIST
DISC:SUMM:DOC:PULMONARY
DISC:SUMM:DOC:RESIDENT
DISC:SUMM:DOC:STAFF PHYSICIAN
DISC:SUMM:DOC:STAFF SURGEON
DOC:ER CARE
DOC:GERIATRIC ATTENDING NOTE
DOC:PSYCHRESIDENT NOTE
EDUC/TRNING FOR VET/FAMILY
EOL Issues
EOL:CARE
EOL:CAUSE OF DEATH
EOL:DEATH:DYING
EOL:DEATH:POST MORTEM
EOL:FAMILY INVOLVEMENT
EOL:futility of care portal
EOL:HOSPICE/PALL CARE
EOL:TERMINAL CONDITION
Ethics Issues
ETHICS:ERN:DATE
ETHICS:ERN:DOC:STAFF PHYSICIAN
ETHICS:ERN:ECM:DOC:ATTENDING
ETHICS:ETFU:ECM:SW
ETHICS:ETFU:GPY:ECM
ETHICS:FAMILY INVOLVED
ETHICS:NAT ETHICS CNTR
ETHICS:REFERRAL REASON
ETHICS:REFERRAL/CONSULT
ETHICS:TEAM ASSESSMENT
ETHICS:TEAM MEMBERS PRESENT
ETHICS:TEAM RECOMMENDATIONS

FINANCE:COMP & PENSION EXAM:DOC
FINANCE:ISSUES
FINANCE:MEDICARE COVERAGE
FINANCE:NOT SERVICE CONNECTED
FINANCE:SERVICE CONNECTED
Form Rel - SS
Form Rel - VS
INTERDISTEAMNOTE:CHP:ETHICS
INTERDISTEAMNOTE:NRS
LIFESTYLE:AGE ISSUE
LIFESTYLE:BELIEFS/VALUES
LIFESTYLE:BELIEFS/VALUES:REFUSE
TRANSFUSIONS
LIFESTYLE:HOMELESS:SHELTERS
LIFESTYLE:MOTORCYCLE CRASH
LIFESTYLE:NARCOTICS CONTRACT
LIFESTYLE:NEEDLE
STICK:HIV:SUBSTANCES
LIFESTYLE:NICOTINE
LIFESTYLE:NO SHOW FOR APPT
LIFESTYLE:NUTRITION ISSUES
LIFESTYLE:PROBLEM BEHAVIOR
LIFESTYLE:QOL
LIFESTYLE:SEXUAL BEHAV ISSUES
LIFESTYLE:SLEEP PATTERNS
LIFESTYLE:SUBS ABUSE:ISSUES?
LIFESTYLE:SUBS ABUSE:SELF
MEDICATING?
LIFESTYLE:SUBS ABUSE:WITHDRAWAL
MEDCOND: HX
MEDCOND: PHYSICAL HEALTH
MEDCOND:ASPIRATION PROBLEMS
MEDCOND:ASSESSMENT &/or PLAN
MEDCOND:CAD:CORONARY ARTERY
DISEASE
MEDCOND:CHF:CONGEST HEART
FAILURE
MEDCOND:CHRONIC CONDITION
MEDCOND:CLINWARNING:DOC:PRIMAR
Y CARE
MEDCOND:COMATOSE
MEDCOND:COMMUN CAPACITY
MEDCOND:COMORBID-MULT ISSUES
MEDCOND:CRISIS
MEDCOND:CURRENT
MEDCOND:EMER ROOM CARE
MEDCOND:EXTUBATED
MEDCOND:FALL RISK
MEDCOND:FAMILY HX
MEDCOND:HX
MEDCOND:ICU

MEDCOND:IMPROVED
MEDCOND:INFECTION
MEDCOND:INTUBATED
MEDCOND:MOBILITY
MEDCOND:OBESITY
MEDCOND:PROGNOSIS
MEDCOND:RESPIRATION PROBS & SOB
MEDCOND:STROKE:CARDIAC
No need to console
PAIN:ASSESSMENT
PAIN:LEVEL
PAIN:MGT
PAIN:MGT:DOC:STAFF PHYSICIAN
PAIN:REPORTED
PERSONHOOD INFO
PHONE CONTACT:DOC:STAFF PHYSICIAN
PHONE CONTACT:MED
CLERK:MORPHINE
PN:ADMIN:NO SHOW FOR APPT
PN:CHIEF OF STAFF:NARCOTICS
PN:DATE OF PROGRESS NOTE
PN:DOC:ATTENDING
PN:DOC:CHIEF, PRIMARY CARE
PN:DOC:GERIATRIC ATTENDING
PN:DOC:INTERNAL MED
PN:DOC:PRIMARY CARE NOTE
PN:DOC:PSYCHIATRIC NOTE
PN:DOC:STAFF PHYSICIAN
PN:LOCAL TITLE:ADMISSION
PN:LOCAL TITLE:ATTENDING
PN:LOCAL TITLE:CHAPLAIN
PN:LOCAL TITLE:COMMUNITY CARE
PN:LOCAL TITLE:CRITICAL CARE
PN:LOCAL TITLE:DISCHARGE
PN:LOCAL TITLE:EMERGENCY/ER
PN:LOCAL TITLE:ETHICS
PN:LOCAL TITLE:GERIATRIC
PN:LOCAL
TITLE:HISTORY&PHYSICAL/H&P
PN:LOCAL TITLE:INTERDISCIPLINARY
PN:LOCAL TITLE:INTERNAL MED
PN:LOCAL TITLE:MRSA INFECTION
PN:LOCAL TITLE:NEUROLOGY
PN:LOCAL TITLE:NURSING
PN:LOCAL TITLE:PSYCHIATRY
PN:LOCAL TITLE:RESIDENT MED CARE
PN:LOCAL TITLE:RESTRAINT
PN:LOCAL TITLE:SOCIAL WORK
PN:LOCAL TITLE:STAFF OF VAMC
PN:LOCAL TITLE:STAFF SURGEON
PN:STANDARD TITLE

PRESCRIBED SUBSTANCE
PRESCRIPTION REQUEST
PSYCHOSOC:AFFECT/EMOTION
PSYCHOSOC:ASSESS/PLAN NOTE
PSYCHOSOC:CONFLICT: w/VA STAFF
PSYCHOSOC:CONFLICT:w/ PEERS
PSYCHOSOC:FAMILY HX
PSYCHOSOC:ISOLATION
PSYCHOSOC:MH:ALZHEIMERS
PSYCHOSOC:MH:ASSESSMENT
PSYCHOSOC:MH:BORDERLINE
PERSONALITY
PSYCHOSOC:MH:CAPACITY&STATUS
PSYCHOSOC:MH:COGNITIVE LOSS
PSYCHOSOC:MH:DEMENTIA
PSYCHOSOC:MH:DEPRESSION
PSYCHOSOC:MH:DSM ASSESS
PSYCHOSOC:MH:HX
PSYCHOSOC:MH:MSE
PSYCHOSOC:MH:PARANOIA
PSYCHOSOC:MH:SCHIZOPHRENIA
PSYCHOSOC:MH:SUICID/ HOMICID
IDEATION?
PSYCHOSOC:OBJECTIVE NOTE
PSYCHOSOC:SOCIAL HX
PSYCHOSOC:SUBJECTIVE NOTE
REL:FORML:CHP-FAMILY
REL:FORML:CHP-VET
REL:FORML:COMM/BEHAV PROBS
REL:FORML:DOC-DOC
REL:FORML:DOC-FAMILY
REL:FORML:DOC-NURS
REL:FORML:DOC-POA
REL:FORML:DOC-SW
REL:FORML:DOC-VAMC STAFF
REL:FORML:DOC-VET
REL:FORML:MED STDNT-FAMILY
REL:FORML:MED STDNT-VET
REL:FORML:NURS-FAMILY
REL:FORML:NURS-NURS
REL:FORML:NURS-VET
REL:FORML:PHYS ASST-FAMILY
REL:FORML:PHYS ASST-NURS
REL:FORML:PHYS ASST-VET
REL:FORML:SW-FAMILY
REL:FORML:SW-NURS
REL:FORML:SW-VET
REL:FORML:VA-EXTERN SERV/SOURCE
REL:FORML:VAMC-FAMILY
REL:FORML:VAMC-VHA SYS
REL:FORML:VAMC STAFF-VET

REL:FORML:VAMC TEAM
REL:FORML:VHAMC-FAMILY
REL:FORML_CHF OF STAFF-VET
REL:INFORML:BROTHER
REL:INFORML:COMM/BEHAV PROBS
REL:INFORML:COUSIN
REL:INFORML:DAUGHTER
REL:INFORML:DHGT-IN-LAW
REL:INFORML:FAMILY:HX
REL:INFORML:FAMILY:INVOLVED
REL:INFORML:FATHER
REL:INFORML:FATHER-IN-LAW
REL:INFORML:GIRLFRIEND
REL:INFORML:MOTHER

REL:INFORML:NIECE
REL:INFORML:PEERS
REL:INFORML:RELS CONTACT PROBS
REL:INFORML:SIBLING-SIBLING
REL:INFORML:SIGNIF OTHER
REL:INFORML:SISTER
REL:INFORML:SISTER-IN-LAW
REL:INFORML:SON
REL:INFORML:SPOUSE
REL:INFORML:STEP-DAUGHTER
REL:INFORML:STEPSON
REL:VET AGENCY LEVEL?
REL:VET:APPROP AUTONOMY?
REPORTS:DATE OF REPORT

Appendix D. Study One Code Families/Categories

Code Family: Vet's Capacity – Mental

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific Software\ATLSti\Te...\cgrelethics_10_08.hpr5]

Codes (14): [PSYCHOSOC:ISOLATION] [PSYCHOSOC:MH:ALZHEIMERS]
[PSYCHOSOC:MH:ASSESSMENT] [PSYCHOSOC:MH:BORDERLINE PERSONALITY]
[PSYCHOSOC:MH:CAPACITY&STATUS] [PSYCHOSOC:MH:COGNITIVE LOSS]
[PSYCHOSOC:MH:DEMENTIA] [PSYCHOSOC:MH:DEPRESSION]
[PSYCHOSOC:MH:DSM ASSESS] [PSYCHOSOC:MH:HX] [PSYCHOSOC:MH:MSE]
[PSYCHOSOC:MH:PARANOIA] [PSYCHOSOC:MH:SCHIZOPHRENIA]
[PSYCHOSOC:MH:SUICID/ HOMICID IDEATION?]

Quotation(s): 1045

Code Family: Vet's Capacity - Physical

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific Software\ATLSti\Te...\cgrelethics_10_08.hpr5]

Codes (11): [MEDCOND:EMER ROOM CARE] [MEDCOND:EXTUBATED]
[MEDCOND:FALL RISK] [MEDCOND:FAMILY HX] [MEDCOND:HX] [MEDCOND:ICU]
[MEDCOND:IMPROVED] [MEDCOND:INFECTION] [MEDCOND:INTUBATED]
[MEDCOND:MOBILITY] [MEDCOND:OBESITY]

Quotation(s): 225

Code Family: Forml-Forml Relations

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific Software\ATLSti\Te...\cgrelethics_10_08.hpr5]

Codes (13): [CN:DOC:PSYCHRESIDENT] [CN:DOC:RHEUMATOLOGY]
[ETHICS:REFERRAL/CONSULT] [INTERDISTEAMNOTE:NRS] [REL:FORML:DOC-DOC]

[REL:FORML:DOC-NURS] [REL:FORML:DOC-SW] [REL:FORML:DOC-VAMC STAFF]
[REL:FORML:NURS-NURS] [REL:FORML:PHYS ASST-NURS] [REL:FORML:SW-NURS]
[REL:FORML:VAMC-VHA SYS] [REL:FORML:VAMC TEAM]

Quotation(s): 690

Code Family: Forml-Vet Relations

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific
Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (9): [PSYCHOSOC:CONFLICT: w/VA STAFF] [REL:FORML:CHP-VET]
[REL:FORML:DOC-VET] [REL:FORML:MED STDNT-VET] [REL:FORML:NURS-VET]
[REL:FORML:PHYS ASST-VET] [REL:FORML:SW-VET] [REL:FORML:VAMC STAFF-
VET] [REL:FORML_CHF OF STAFF-VET]

Quotation(s): 754

Code Family: Vet's Care Desired

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific
Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (6): [AD:DISCUSSED W/ VET] [AD:DPOA:MPOA:POA?] [AD:HONORED]
[AD:LIVING WILL] [AD:NO CHANGES] [AD:SW]

Quotation(s): 351

Code Family: Vet's Care Delivered

HU: cgrelethics_10_08

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Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (32): [CARE:ADL's & IADL's] [CARE:ASSISTED LIVING] [CARE:COMFORT
CARE ONLY] [CARE:ECRC SCREEN?] [CARE:ECRC:EXTENDED CARE?]
[CARE:FAMILY] [CARE:FOLLOW UP CARE] [CARE:HOME] [CARE:INFORMAL]
[CARE:LEVEL CHANGE] [CARE:LEVEL OF CARE] [CARE:NURSING HOME]
[CARE:PLACEMENT] [CARE:PLACEMENT:HOME] [CARE:RESTRAINT & SECLUSION]

[CARE:REVERSIBLE DECISION] [CARE:SPOUSAL] [CARE:TOTAL CARE]
[CARE:TRANSFER] [CHRONIC CONDITION] [MEDCOND:EMER ROOM CARE]
[MEDCOND:ICU] [PAIN:MGT:DOC:STAFF PHYSICIAN]

Quotation(s): 878

Code Family: Vet's Lifestyle - Healthy

HU: cgrelethics_10_08

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Codes (5): [CN:NURS:COMMUN/HOME HEALTH] [CN:NUTRITIONIST] [CN:PHYS
THER] [MEDCOND: PHYSICAL HEALTH] [REL:INFORML:FAMILY:INVOLVED]

Quotation(s): 401

Code Family: Vet's Lifestyle - Unhealthy

HU: cgrelethics_10_08

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Codes (9): [LIFESTYLE:HOMELESS:SHELTERS] [LIFESTYLE:MOTORCYCLE
CRASH] [LIFESTYLE:NARCOTICS CONTRACT] [LIFESTYLE:NEEDLE
STICK:HIV:SUBSTANCES] [LIFESTYLE:NICOTINE] [LIFESTYLE:NO SHOW FOR
APPT] [LIFESTYLE:PROBLEM BEHAVIOR] [LIFESTYLE:SEXUAL BEHAV ISSUES]
[LIFESTYLE:SUBS ABUSE:ISSUES?]

Quotation(s): 91

Code Family: Ethics - Evidence

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific
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Codes (5): [ETHICS:FAMILY INVOLVED] [ETHICS:REFERRAL REASON]
[ETHICS:REFERRAL/CONSULT] [ETHICS:TEAM ASSESSMENT] [ETHICS:TEAM
RECOMMENDATIONS]

Quotation(s): 79

Code Family: Ethics - Ambiguous

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific
Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (3): [ETHICS:NAT ETHICS CNTR] [ETHICS:TEAM RECOMMENDATIONS]
[PSYCHOSOC:CONFLICT: w/VA STAFF]

Quotation(s): 47

Code Family: Vet's Service-Conn %

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific
Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (1): [DG:SERVICE CONNECTED DISABILITIES]

Quotation(s): 35

Code Family: EOL - Cure

HU: cgrelethics_10_08

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Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (5): [AD:FULL CODE] [CARE:TOTAL CARE] [MEDCOND:EMER ROOM
CARE] [MEDCOND:ICU] [MEDCOND:INTUBATED]

Quotation(s): 166

Code Family: EOL - Comfort

HU: cgrelethics_10_08

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Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (9): [AD:DNR] [AD:DNR RESCINDED] [AD:DNR:CARE WITHHELD]
[AD:DNR:DETAILS] [AD:DNR:DOC:RESIDENT] [AD:DNR:DOC:STAFF PHYSICIAN]
[AD:DNR:GERPSYCH] [CARE:COMFORT CARE ONLY] [CARE:TX WITHHELD]
Quotation(s): 349

Appendix E. Study Two Code Families/Categories

Code Family: Formal-Informl Rels - Collab

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific Software\ATLSti\Te...\cgrelethics_10_08.hpr5]

Codes (20): [ETHICS:REFERRAL/CONSULT] [ETHICS:TEAM RECOMMENDATIONS] [REL:FORML:CHP-FAMILY] [REL:FORML:CHP-VET] [REL:FORML:DOC-FAMILY] [REL:FORML:DOC-POA] [REL:FORML:DOC-VET] [REL:FORML:MED STDNT-FAMILY] [REL:FORML:MED STDNT-VET] [REL:FORML:NURS-FAMILY] [REL:FORML:NURS-VET] [REL:FORML:PHYS ASST-FAMILY] [REL:FORML:PHYS ASST-VET] [REL:FORML:SW-FAMILY] [REL:FORML:SW-VET] [REL:FORML:VA-EXTERN SERV/SOURCE] [REL:FORML:VAMC-FAMILY] [REL:FORML:VAMC STAFF-VET] [REL:FORML_CHF OF STAFF-VET] [REL:INFORML:FAMILY:INVOLVED]

Quotation(s): 1247

Code Family: Forml-Informl Rels - Conflict

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific Software\ATLSti\Te...\cgrelethics_10_08.hpr5]

Codes (2): [PSYCHOSOC:CONFLICT: w/VA STAFF] [REL:INFORML:COMM/BEHAV PROBS]

Quotation(s): 81

Code Family: Ethics Team - Supp Staff

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific Software\ATLSti\Te...\cgrelethics_10_08.hpr5]

Codes (5): [ETHICS:ERN:DOC:STAFF PHYSICIAN] [ETHICS:ETFU:ECM:SW]
[ETHICS:REFERRAL/CONSULT] [ETHICS:TEAM ASSESSMENT] [ETHICS:TEAM
RECOMMENDATIONS]

Quotation(s): 47

Code Family: Ethics Team - Supp Family

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific
Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (3): [ETHICS:FAMILY INVOLVED] [ETHICS:TEAM RECOMMENDATIONS]
[REL:FORML:VAMC TEAM]

Quotation(s): 206

Code Family: Advan Dir - Care Req

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific
Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (5): [AD:DNR:DETAILS] [AD:FULL CODE] [AD:NO CHANGES] [AD:NRS]
[AD:SW]

Quotation(s): 167

Code Family: Advan Dir - Care Withheld

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific
Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (4): [AD:DNR] [AD:DNR:CARE WITHHELD] [CARE:COMFORT CARE ONLY]
[CARE:TX WITHHELD]

Quotation(s): 323

Code Family: Psychosoc - Affective

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific Software\ATLAS\Te...\cgrelethics_10_08.hpr5]

Codes (3): [PSYCHOSOC:AFFECT/EMOTION] [PSYCHOSOC:CONFLICT: w/VA STAFF] [PSYCHOSOC:CONFLICT:w/ PEERS]

Quotation(s): 18

Code Family: Psychosoc - Soc/Relational

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific Software\ATLAS\Te...\cgrelethics_10_08.hpr5]

Codes (3): [PSYCHOSOC:FAMILY HX] [PSYCHOSOC:SOCIAL HX] [PSYCHOSOC:SUBJECTIVE NOTE]

Quotation(s): 81

Code Family: Caregiving - Cure

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific Software\ATLAS\Te...\cgrelethics_10_08.hpr5]

Codes (4): [AD:FULL CODE] [CARE:FOLLOW UP CARE] [CARE:GOALS] [CARE:TOTAL CARE]

Quotation(s): 53

Code Family: Caregiving - Comfort

HU: cgrelethics_10_08

File: [C:\Documents and Settings\Jim\My Documents\Scientific
Software\ATLAsTi\Te...\cgrelethics_10_08.hpr5]

Codes (4): [AD:DNR] [CARE:COMFORT CARE ONLY] [CARE:TX WITHHELD]
[PAIN:REPORTED]

Quotation(s): 325