Relationship Based Care: Exploring the Manifestations of Health as Expanding Consciousness within a Patient and Family Centered Medical Intensive Care Unit

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RELATIONSHIP BASED CARE: EXPLORING THE MANIFESTATIONS OF
HEALTH AS EXPANDING CONSCIOUSNESS WITHIN A PATIENT AND FAMILY
CENTERED MEDICAL INTENSIVE CARE UNIT

a dissertation

by

LILLIAN VIRGINIA ANANIAN

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for the degree of

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Abstract

Relationship based Care: Exploring the Manifestations of Health as Expanding Consciousness within a Patient and Family Centered Medical Intensive Care Unit

Lillian Virginia Ananian
Dorothy Jones

A family’s unique way of being, formulated through social, economic, environmental and political factors, becomes fractured during a loved one’s critical illness. Family members experience burdensome physical and emotional symptoms as they transition through the marked uncertainty endemic to high acuity illness. For some, this burden results in long term psychiatric disturbances.

Assessment tools and interventions have been proposed for family members experiencing a loved one’s critical illness. However, ongoing suffering suggests inherent limitations within these reductionist approaches. The need for a more encompassing disciplinary perspective is suggested.

Margaret Newman’s (1986, 1994, 2008) theory of Health as Expanding Consciousness (HEC) and its praxis research method was employed to explore relationship based care among intensive care unit (ICU) family members and registered nurses. HEC retains person/environmental integrity through unfolding of unitary knowledge via exploration of meaning. Additionally, its holistic perspective aligns philosophically with the belief in nursing science as the study of caring in the human health experience, endorsing both the mutuality of the nurse/client relationship and pattern recognition’s capacity to inspire transformational growth.
The study was performed in an eighteen bed medical ICU in the northeast region of the United States. This unit’s design includes an integrated critical/palliative care model. Exploration of the study’s two research questions was accomplished using the practice and research components of HEC within a sample of eight family members and six registered nurses.

Results demonstrated family members’ capacity to achieve consciousness expansion within the context of a loved one’s critical illness. Registered nurses revealed their ability to steadfastly partner with both patients and families. Repetitive elements distinguished as thematic commonalities were recognized among both family member and registered nurse participants. Additionally, thematic integration between family members and registered nurses was appreciated. HEC was found to offer unique insights into caring relationships between ICU family members and registered nurses.
ACKNOWLEDGEMENTS

I am honored to acknowledge the academic contributions provided by both my undergraduate and graduate nursing education; the enlightened academic expansion I gained through Boston College’s nursing doctoral program, including areas such as epistemology, ontology, nursing theory and nursing science; my dissertation committee’s suggestion of dual target populations including both family members and registered nurses within the exploration of Margaret Newman’s Health as Expanding Consciousness; the Massachusetts General Hospital Medical Intensive Care Unit leadership team’s successful implementation of a relationship based patient/family centered care model, and the remarkable patient/family contributions provided by the unit’s registered nurse staff members; and my professional colleagues. I would also like to honor this study’s family member participants, who gave so generously of their time despite having critically ill loved ones.

Finally, I would like to recognize the unwavering devotion of my family, and specifically my mother whose loving belief in me has been simply remarkable.
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CHAPTER ONE

Introduction

Admission to the intensive care unit (ICU) represents a clinically urgent event. High intensity medical, nursing, pharmacologic and technologic interventions are employed to achieve restoration of normal physiologic function. This intensely encompassing approach to critical illness management has led some to consider the ICU as a “health ‘sanctuary’ for recovery” (Cobb et al, 2009, p. 3159). Yet, despite aggressive life support efforts, patient recovery is not assured. Evidence to date suggests that nearly 20% of United States deaths occur during or shortly following an ICU admission (Angus et al, 2004; Curtis, 2008; The SUPPORT Principal Investigators, 1995).

Illness severity coupled with mortality risk contributes to a wide range of burdensome experiences for ICU patients and their families. Critically ill patients report intense and distressful symptoms, including fatigue, confusion, shortness of breath, pain, restlessness, anxiety, sadness, hunger, fear and thirst (Puntillo et al, 2010). Emotional suffering revealed symptomatically as anxiety, stress and depression occurs commonly among loved ones (McAdam & Puntillo, 2009).

The goal of professional nursing has been broadly articulated as the promotion of health and healing (American Nurses Association, 2001). Components of this goal are further delineated to include facilitation of human flourishing and the alleviation of suffering (Willis & Grace, 2011). Achievement of these objectives is revealed through relationship, inextricably linking nurses to the persons for whom they care.

Nursing’s disciplinary goal of fostering human health and healing has not yet been fully achieved among ICU patients’ loved ones. Existing literature has consistently validated family needs. Yet, family members continue to experience emotional suffering, suggesting the importance
of an alternate philosophic lens through which family responses may be contextually appreciated within the ICU family/nurse relationship.

Contemporary nursing authors have espoused disciplinary adoption of person and environmental wholeness (Cowling & Swartout, 2011), shifting nursing science from analysis of individual parts to examination of the whole (Newman, 1999). Health as Expanding Consciousness (Newman, 1986, 1994, 2008) represents a philosophic model employing a hermeneutic phenomenological approach focused on preserving the wholeness of person and environment through the use of pattern recognition to promote expansion of consciousness. To date, no studies have employed this theoretical approach in the exploration of meaning within the critical care experiences of family members and registered nurses.

Background

An ICU admission is universally recognized as a time of crisis for patients and families (Bijttebier et al, 2001; Stayt, 2007). The uncertainty associated with clinically complex illnesses often reverberates emotionally throughout the family (Halm et al, 1993; Kleiber et al, 1994; McClowry, 1992; Titler, Cohen & Craft, 1991). Family responses to the imposed stress of critical illness are manifested by emotional responses such as numbness, terror, isolation and loneliness (Browning & Warren, 2006; Fontana, 2006; Hughes, Bryan & Robbins, 2005; Paul & Rattray, 2008). ICU patients and families experience anxiety (Tracy, Fowler & Magarelli, 1999), depression (Pochard et al, 2005), acute stress disorder (Auerbach et al, 2005) and post-traumatic stress (Corrigan, Samuelson, Fridlund & Thome, 2007; Jones et al, 2004). Work by Azoulay and others (2005) reported a significant relationship between family members at risk for developing post traumatic stress disorder (PTSD) and those who described receiving incomplete information during their loved one’s ICU stay. In addition, patient and family quality of life both during and
following an ICU event is significantly influenced by the relational experience among the patient, family and ICU (Carlet, Garrrouste-Orgeas & Guidet, 2003). Further, researchers have outlined interconnectedness among family emotions and patient outcomes (Maddox, Dunn & Pretty, 2001; Tracy, Fowler & Magarelli, 1999). These findings highlight the importance of integrating clinical and relational care among nurses, patients and families within the human health experience of a critical illness event.

Nurse Patient Relationship-Central to the Mission of the Discipline

Nurses and the persons for whom they care are engaged through relationship. The introduction of intensive care units and their commensurate high intensity care redirected nursing attention from relationship to skill acquisition and the implementation of requisite technical skills, often fracturing the human elements of interpersonal processes. Contemporary acknowledgement of connections between the human aspect of the ICU experience and both clinical and emotional outcomes has renewed interest in and scientific exploration of relationship based care.

Studies acknowledging the emotional interface between ICU patients and their families evolved from nursing science (Hampe, 1975). Molter’s (1979) empiric attention to the family experience was realized through development of the Critical Care Family Needs Inventory (CCFNI). Use of this instrument revealed the need for information, hope, honest and understandable answers to questions, timely family notification of changes in patient status and open visiting (Molter, 1979) among diverse ICU populations (Bijttebier et al, 2000; Kreutzer, Devany Serio & Bergquist, 1994; Mendonca & Warren, 1998; Stillwell, 1984).

While substantial empiric acknowledgement of family needs during a critical care experience has been demonstrated, families report inconsistent caregiver attention to their lived experiences (Verhaeghe, Defloor, Van Zuuren, Duijnstee & Grypdonck, 2005). Families desire greater levels
of decision making support, improved understanding and assistance regarding cultural, spiritual and religious factors, appreciation of the ICU environment’s impact on their experiences and participation during daily rounds and resuscitation events (Davidson et al, 2007). These ongoing and pronounced experiential burdens illuminate the necessity of employing alternate scientific methods in the quest for enhanced understanding of ICU family experiences and, ultimately, for the development of interventions aimed at reducing family member distress.

Philosophic beliefs influence both disciplinary perspectives towards the nature of personhood and the associated research methodologies employed for disciplinary knowledge expansion. Nursing’s philosophic perspective was initially articulated through a holistic conceptualization of person, reflected within Nightingale’s (1969) belief in the interface between person and environment. As clinical science progressed, nursing aligned philosophically with medicine, adopting a more reductionist approach (Erickson, 2007), resulting in the perception of disease as a problem to be overcome. Consequently, persons were perceived as the sum of their parts, and were segregated into components of body, mind, society, emotion and spirit. Margaret Newman (1986) espoused a return to the integrated nature of person through her theoretical conception of Health as Expanding Consciousness (HEC), a process oriented model of scientific exploration which allows for deeper discovery of the inseparable person/environment interface, resulting in consciousness expansion through pattern recognition, and the achievement of human meaning.

Health is considered the process of consciousness expansion, a growth promoting mechanism realized irrespective of one’s clinical condition or medical diagnosis. However, the crisis and uncertainty associated with illness often provide an opportune time for personal reflection. Accordingly, the ineffectiveness of existing behaviors may be recognized and result in individuals’ inspirational advancement towards new awareness and, subsequently, new ways of being.
To date, little is known about either the experiences of meaning among critical care nurses in relationship with families, or family members in relationship with critically ill ones. Further, no study has engaged a hermeneutic phenomenological approach to garner understanding of the interface between ICU family experiences and nursing care within the human health experience of critical illness. Therefore, the purpose of this study is to employ HEC and its nursing praxis research method to explore underlying patterns and the capacity for consciousness expansion among critically ill family members and registered nurses. Details of this theoretical framework will now be provided.

Theoretical Framework: Health as Expanding Consciousness

Health as Expanding Consciousness (HEC) serves as the study’s theoretical model (Newman, 1986, 1994, 2008). Newman’s vision of health and illness as integrated phenomena representing evolving patterns of unitary human consciousness reflects an empiric expansion of Martha Roger’s unitary paradigm. HEC is conceived of as a health paradigm (Newman, 2008). The framework expands nursing’s practice from directed attention to patient symptoms and their diagnoses to a broader perspective of patients as unique individuals with associated patterns, reflecting their underlying wholeness. Persons are considered to be dynamic, and engaged in continuous processes within a larger environmental field. Disease, once considered a problem to be cured, is alternatively perceived as an expression of the individual’s unitary process. Underlying pattern is reflected as consciousness, or the capacity to interact with the larger system (Newman, 2008). Further theoretical support for HEC emanates from the works of Bentov, Bohm, Prigogine, Young and Whitmont (Newman, 2008). Newman’s perspective on human consciousness development is notably aligned with Young’s theory of the evolution of consciousness (Table 1).
Young's (1976) conceptualization of consciousness evolution is perceived as occurring in stages (Newman, 2008). Salient within this process is the potential for human insight achieved at the choice (nadir) point, resulting in recognition that prior ways of being are no longer effective, illuminating the need for change. Introducing Newman’s methodology at the nadir point helps foster human insight through pattern recognition, offering individuals the opportunity to select alternate life choices, allowing greater freedom, growth and consciousness expansion. Newman (1994) has characterized human expansion beyond the nadir as indicative of human growth. Transformative action occurring through consciousness expansion is accelerated by recognizing new growth needs and resolving to engage in the progressive transitions of decision making, action and change.
Table 1-1:

*Young’s Theoretical Construct in Relation to HEC*

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<td><strong>Overview:</strong> Self identity develops until the nadir choice point is reached, offering opportunities to foster higher levels of inner human growth.</td>
<td><strong>Overview:</strong> Health is unitarily related to illness, and represents consciousness expansion.</td>
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<td><strong>Step One:</strong> Potential Freedom.</td>
<td><strong>Step One:</strong> Evolution from a state of potential consciousness</td>
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<td>Potential for freedom emerges through its loss and subsequent movement towards total freedom</td>
<td><strong>Step Two:</strong> Become bound in time</td>
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<td><strong>Step Two:</strong> Binding</td>
<td><strong>Step Three:</strong> Spatial identity is realized</td>
</tr>
<tr>
<td>Everything is regulated, making individual initiative unnecessary</td>
<td><strong>Step Three:</strong> Spatial identity is realized</td>
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<tr>
<td><strong>Step Three:</strong> Centering</td>
<td><strong>Step Four:</strong> Discovery of the true ways of life</td>
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<td>Individual identity is established, leading to the emergence of self-consciousness and self-determination</td>
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Itzhak Bentov’s views of expanding consciousness conceptualize life as a process of consciousness expansion (Bentov, 1977; Bentov, 1978; Newman, 2008). Consciousness is described as the system’s informational capacity reflected through both the quality and quantity of environmental interaction. For Newman, health equates to consciousness expansion, achieved through the generation of unitary knowledge and subsequent personal growth which is promoted through acknowledgement of choice and action, as described below.

Bohm: Implicate Order

Newman’s perceptions of disease as a revelation of underlying life pattern is influenced by Bohm’s theory of implicate order (Bohm, 1980; Newman, 2008). Bohm describes implicate as an invisible, primary underlying pattern. All of life’s tangible elements are considered explications of this implicate order. Information is thought to exist universally and be unrestricted by limitations of space or time, allowing perceptions of implicate order to be acknowledged through human feeling. Observations of the human experience, including those seen in disease, are considered a reflection of the implicate order; part of the expression of the whole.

Prigogine: Theory of Dissipative Structures

Prigogine’s theory of dissipative structures describes a system’s growth capacity within a context of disruption (Newman, 2008; Prigogine, 1976; Prigogine & Stengers, 1984). A system is viewed as an entity, engaged in a process of orderly fluctuation until influenced by a disruptive event when, in response, it begins a new process of self organization. Although perceived as random and disorderly, reorganization represents a system’s advancement and growth. Applied to Newman’s conceptualizations, Prigogine’s theory elucidates disease as a mechanism through which human consciousness expansion may occur.

Whitmont: Pattern Representation
Whitmont (1994) posits the existence of individual patterns as representations of unique innate and intrinsic forces (Newman, 2008). Inherent within humanity is the expectation of growth and change, both of which are potentiated by a pre-existing force. As a result, it is possible for a disease experience to serve as a mechanism through which human enhancement occurs. Human response to illness includes attempts to repair biopsychosocial causes, but also includes transformative acts which propel individuals toward human growth, even in the absence of physical health restoration.

Environment of Care

The care environment is conceptualized as one in which patient and family centered care is practiced within an integrated palliative and critical care environment. This setting addresses patient and family centered care by providing patients, families and/or loved ones the opportunity to represent the patient’s unique individuality through expressions of goals and preferences (National Consensus Project for Quality Palliative Care, 2004). Further, it encompasses a structural practice paradigm focused on both the provision of life saving patient interventions with concomitant attention to patient, family and loved one’s emergent emotional responses throughout the critical illness experience (Nelson et al, 2010 a).

Relationship Based Care

Patient and family centered practice actualized as nursing’s caring engagement with patients and loved ones’ unique ways of being during a critical illness event serves as the study’s model of care delivery. The nurse patient relationship (NPR) and relationship based care represent established models of caring engagement. NPR, an interpersonal process model, encompasses a defined trajectory consisting of a beginning phase focused on the development of trust; a working or middle phase; and a termination phase (Hagerty & Patusky, 2003; King, 1981; Paterson &

Caring within the Human Experience

An articulated focus is requisite for disciplinary knowledge development (Newman, 2008; Newman, Sime & Corcoran-Perry, 1991; Picard & Jones, 2005). While strong evidence of an alliance among caring, health and health experience as metaparadigmatic concepts germane to nursing’s focus existed, conceptual integration was not achieved until Newman, Sime & Corcoran-Perry’s (1991) description of nursing science as the study of caring in the human health experience. This unitary perspective of caring, humanity and health heightens attention to the holistic connection between individuals and their universe, revealing a reality that is different from and greater than the summative expression of each (Florczak, Falkenstern & Baumann, 2010; Newman 1994, 2005, 2008). Further, this conceptualization represents evolutionary development of disciplinary knowledge from traditional scientific methods to a unitary perspective of the whole, accompanied by pattern recognition as the approach to knowledge, and mutuality as the mechanism through which unfolding, insight and personal action evolves. When applied intentionally by nurses caringly engaged with others, transformational discoveries and
understandings of the human health experience may emerge (Newman, Smith, Pharris & Jones, 2008).

Appreciating pattern as an expression of the underlying whole preserves nursing’s unitary focus, transitioning attention from the chaos of disease to the potentiality of personhood. Required within this alternate paradigm is creative facilitation of others’ evolution to higher levels of consciousness (Newman, 2008). Reflection on meaningful life events serves to reveal underlying pattern and associated growth opportunities, manifested in a multiplicity of expressions including self awareness, enhanced life meaning and growth in one’s capacity to connect with both others and the world.

Understanding disease as a reflection of one’s implicate pattern requires a holistic research design. The unitary-transformative paradigm, illuminated by Newman (2008), Newman, Sime and Corcoran-Perry (1991) and Picard & Jones (2005), serves as an approach to human science research which allows for exploration of pattern and wholeness while simultaneously providing for the inclusion of more explicate perspectives. The researcher-participant engages in a dialectic search for meaning through the researcher-participant relationship which reflects receptivity, reciprocity and a feeling of oneness, with insight achieved as pattern is revealed through an affiliation which supports unfolding and mutuality, leading to the realization of action possibilities (Newman, 2008). This dynamic interface of theory, research and practice has been described by Newman as nursing praxis.

Application of HEC within the nurse/patient/family relationship utilizes nursing praxis to promote pattern revelation, through which information about the whole is obtained and transformation is facilitated (Florczak, Falkenstern & Baumann, 2010; Newman, 1994, 2005, 2008). Patient/family/environmental unfolding reveals unique expressions of health exclusive of
the medical diagnosis or illness intensity. Because humans are dynamic and capable of change through awareness, exposure to pattern as revealed by family/nurse dialogue allows for the occurrence of pattern recognition through human enlightenment, liberating individuals to the possibility of growth and the potential for human transformation. Newman’s disciplinary focus conveys nursing’s commitment to caring in both a moral and ethical sense (Newman, Sime & Corcoran-Perry, 1991). The integration of the patient and family’s unique way of being in concert with the study’s theoretical framework, care environment and model of nursing care delivery is illustrated in Figure 1-1.
Figure 1-1.

*Proposed Impact of Critical Illness on the Family Unit*
Significance

This study is significant in that it aims to reveal what is known about the experiences of critically ill families and their nurses. Further, it seeks to expand nursing knowledge by applying Newman’s theory of Health as Expanding Consciousness to the experience of ICU families and the registered nurses caring for their loved ones. The epistemologic perspective of wholeness represented via a unitary paradigm within a critical care environment will advance nursing knowledge and promote nursing science development by enhancing understanding of mechanisms directed towards promotion of human flourishing during critical illness.

Patient centered care recognizes the interface between the individual nature of personhood and the system of health care delivery. The Institute of Medicine (2001) has defined patient centered care as encompassing “… qualities of compassion, empathy, and responsiveness to the needs, values and expressed preferences of the individual patient” (Institute of Medicine, 2001, p. 48). Gerteis, Edgman-Levitan and Daley (1993) describe the patient centered model as including attributes such as information sharing opportunities, vigorous patient involvement in decision making, thorough attention to physical and emotional needs, maintenance or improvement of quality of life, respect for and incorporation of cultural specificities, and full appreciation of the dynamic nature among these elements.

Studies exploring outcomes of information sharing employing early family meetings among family members and clinicians, along with other associated processes of information sharing, have revealed significant findings including reductions in ICU length of stay for those patients at high risk for death, earlier access to appropriate palliative care consults, and reductions in burdensome family emotions including anxiety, depression and PTSD (Lautrette et al, 2007; Lilly et al, 2000; Lilly, Sonna, Haley & Massaro, 2003). With recognition of the dynamic interplay occurring
between the unique nature of the individual and personal experiences of critical illness, further pilot work has suggested correlations between high levels of optimism, increased patient/family satisfaction and perceptions of high levels of affiliation with ICU physicians (Auerbach et al, 2005). Together, these studies begin to suggest the importance of personhood and meaning within the critical care environment, phenomena which may be more fully understood using a participatory methodology allowing for exploration of pattern revealed through the person – environment connection (Picard & Jones, 2005). Purposeful exploration of meaning amid the crisis of critical illness via Newman’s praxis methodology creates a mutuality which allows for unfolding of pattern, with further potential for insight, clarity, meaning, confidence and transformation to higher levels of consciousness for families and nurses (Newman, 2005). Further, it will expand disciplinary knowledge on how best to promote caring in the human health experience of critical illness.

This study’s aim is to uncover experiences of critically ill families and their nurses employing the interpretive approach of pattern recognition to encapsulate the human lived experience of a critical illness. The purpose of the study is to employ the hermeneutic phenomenologic approach within the HEC model to explore experiences of care within the ICU. The following research questions will be addressed:

1. What is the family experience of relationship based care when a critically ill loved one is receiving care within a medical intensive care unit environment?
2. What experiences are revealed by nurses practicing within a relationship based practice model when caring for families in a medical intensive care unit environment?
Assumptions

Although experiences vary, it can be assumed that family descriptions will authentically reflect their experiences and illuminate the meaning of ICU care experiences. Additionally, it is assumed that clinical nursing staff’s descriptions will reveal their perceptions of lived experiences of care provision. Finally, it is assumed that families and nurses will offer honest reflections of their experiences.

Summary

Contemporary critical care units serve patients with intense clinical needs. While attending to these severe physiologic challenges is essential, care processes must also be expanded to patients’ loved ones. Failure to do so may be emotionally deleterious to both patients and families.

Little is known about the nature of meaning within the critical care experience. Further, holistic examination of the interface among families’ unique ways of being while situated within an integrated critical and palliative care environment and engaged with nurses providing relationship based care has not been undertaken. This study seeks to provide nursing science contributions through exploration of pattern and its influence on achieving consciousness expansion among ICU families and clinical nurses within the paradigmatic approach of Margaret Newman’s Health as Expanding Consciousness.
CHAPTER TWO

Introduction

Since inception, the goal of intensive care services has been to decrease short term patient mortality during an episode of high acuity illness (Angus & Carlet, 2003). Despite forty years of technologic advancements, ICU mortality remains unacceptably high (Angus et al, 2004). The impact of critical illness coupled with a high risk for death engulfs the entire family unit, resulting in emotional distress among loved ones.

To gain a comprehensive view of the ICU experience, including a more complete understanding of elements necessary for successful models of patient/family support, utilization data and its requisite science must be integrated with the associated human experiences and responses and behaviors of patients and families. A deeper understanding of the ICU experience’s impact on patient and family long term health and well being has been noted as important arenas of future focus (Angus & Carlet, 2003). Understanding of the human experience of ICU patients and their families requires further exploration.

In this chapter, the extant literature related to patients and families within the ICU environment is introduced. Initial work describing experiences, behaviors and responses is discussed, followed by exploration of meaning within the context of critical care experiences, and perceived relationships among behaviors and symptom manifestations. Information describing the state of the science regarding patient and family centered care follows. A review of best practice strategies coupled with available evidence and its associated literature is then provided. Finally, findings from studies employing Newman’s HEC praxis methodology are explored.
Family Responses to ICU Patient Experiences

Critical illness threatens the integrity of intimate family bonds by placing patients at the edge of death or disability. Illness severity frequently limits a patient’s capacity to participate in decision making, offer thoughtful reflection on one’s perceived needs or express wishes for life sustaining treatments. Accordingly, families are often called upon to serve as patient proxy, reflecting the family’s societal role of assisting in the management of a family member’s experience of health and illness (Litman, 1974). Implementation of this important and socially prescribed role often adversely impacts family wellbeing (Van Horn & Kautz, 2007). Consequently, family members may experience profound emotional and physical burdens.

Family Suffering and the ICU Experience

Scientific exploration of family suffering within the ICU, including emotional distress (Auerbach et al 2005), burdensome experiences of fatigue, sadness and fear (McAdam, Dracup, White, Fontaine and Puntillo, 2010), psychiatric disorders (Pochard et al, 2005) and altered family roles has resulted in heightened attention to family centered care (Azoulay et al, 2001; Curtis, Patrick, Shannon, Treece, Engelberg & Rubenfeld, 2001; Heyland et al, 2002; Van Horn & Tesh, 2000). Specific modalities of care have been recommended for the provision of family support (Kentish-Barnes, Lemiare, Chaize, Pochard & Azoulay, 2009), uniting nurses in relationship with both patients and families. Knowledge of family support strategies has been gleaned from both empiric exploration of family needs (Molter, 1979) and evidence based family support recommendations, including patient proximity, open visiting and information exchange among patients, families and clinicians (Davidson et al, 2007).

Nursing’s initial scientific examination of ICU families explored family member experiences and responses. Wives whose husbands were critically ill identified needs including the need for
information, the ability to release feelings, the need to be accepted and supported by clinicians, and relationship focused responses including the need to be with their dying husbands, to help their husbands and to be assured that their husbands’ physical and emotional comfort were being addressed (Hampe, 1975).

Critical Care Family Needs Inventory

Development of a Critical Care Family Needs Inventory (Molter, 1979) represented the next substantial contribution to nursing science. The Critical Care Family Needs Inventory (CCFNI) is described as a reliable and valid 45 item family needs inventory with internal consistencies ranging from 0.62 and 0.80 (Bijttebier et al, 2000; Leske, 1991; Neabel, Fothergill-Bourbonnais & Dunning, 2000). Five domains have been reported through factor analysis, including support, comfort, information, proximity and assurance (Leske, 1991). Notably, all items did not load similarly during a replicated factor analysis performed by Bijttebier and colleagues (Bijttebier et al, 2000), indicating the need for ongoing item analyses. Further, various inconsistencies in its use have been noted, including patient condition and trajectory of illness during tool completion (Paul & Rattray, 2008). The CCRNI has consistently demonstrated results reflecting the family’s need for accurate and comprehensible information, an important factor in the development of hope (Verhaeghe et al, 2005). Three decades of CCFNI data offers substantial insight into the relationship between a critical care event and subsequent family responses, as noted below.

CCFNI: Information

To date, studies have confirmed the need for information as the most substantive family need when experiencing a loved one’s critical illness (Bijttebier, Vanoost, Delva, Ferdinande & Frans, 2001; Daley, 1984; Davis, 1994; Engli & Kirsivali, 1993; Freichels, 1991; Hickey, 1990; Kleinpell & Powers. 1992; Kreutzer, Devany, Serio & Bergquist, 1994; Lee & Lau, 2003; Leske, 1986;

**CCFNI: Emotions**

Emotional responses are germane, with expressions of hope serving as a major family response to a loved one’s illness (Verhaeghe et al, 2005). At various times, the need for hope is so substantial that it supersedes informational needs (Campbell, 1988; Davis, 1994; Freichels, 1991; Kreutzer et al, 1994; Mathis, 1984; Molter, 1979). Joining hope is the need for continued provider reassurance, revealed through requests to be called at home for changes in a loved one’s condition, and for frequent reassurance that the patient is receiving both the best possible care and provider attention to overall patient comfort (Bijttebier et al, 2001; Daley, 1984; Davis, 1994; Engli &

**CCFNI: Social**

The patient/family interface is reflected in the expression of social needs, with proximity to loved ones serving as most significant (Verhaeghe et al, 2005). Families perceive proximity to include the ability to be physically close to the patient and to be able to see the patient regularly (Bijttebier et al, 2001; Daley, 1984; Davis, 1994; Engli & Kirsivali, 1993; Freichels, 1991; Hickey, 1990; Kleinpell & Powers, 1992; Kreutzer et al, 1994; Lee & Lau, 2003; Leske, 1986; Mendonca & Warren, 1998; O’Neill Norris & Grove, 1986; Price et al, 1991; Rukholm et al, 1991; Serio et al, 1997; Spatt et al, 1986; Testani-Dufour et al, 1992; Verhaeghe et al, 2005; Warren 1993). While this becomes even more substantial as patient acuity increases (Stillwell, 1984), it remains an important factor even as the high acuity phase concludes (Davis, 1994; Freichels, 1991).

**CCFNI: Practical**

Response to Illness: The Lived Experience

Data expanding understanding beyond distinct needs towards meaning and purpose within the critical illness experience is limited. Yet, relational links between relatives’ needs, met and unmet needs, coping and stress responses have been suggested (Paul & Rattray, 2008). Fry and Warren (2007) engaged in a Heideggerian hermeneutic phenomenological study of family lived experiences in the critical care waiting room. Their results confirmed the family’s need for information, but uncovered the distinct value of truthful, prognostic information on facilitating family endurance. Proximity to the patient was also acknowledged as important, but was further illuminated as a mechanism for families to serve as the patient’s voice. Finally, the need to remain positive during the process of the ICU experience existed as a powerful coping mechanism for both patient and family.

Response to Illness: Conceptual Exploration

Using qualitative exploration of conceptual affiliations, Morse and Penrod (1999) engaged in a scientific exploration of enduring, uncertainty, suffering and hope in situations of unexpected illness or injury. Their findings, described below, revealed the emergence of a dynamic, progressive process beginning with the experience of enduring and continuing through uncertainty, suffering and, finally, to hope, with levels of awareness serving as the mechanism through which personal conceptual progression was achieved.

Awareness, an emotional level of knowing that lacks full cognitive comprehension, places the individual within the emotionally protective space of enduring. As the level of knowing elevates to recognition, beginning comprehension or “sinking in” emerges, allowing the person to establish a tentative goal and to move forward into a state of uncertainty. The experience of suffering occurs through acknowledgement, a level of knowing that allows for realistic appreciation of the event’s
impact on one’s past, present and altered future. Finally, as knowing moves into the realm of acceptance, acknowledgement of the past, present and future helps advance the individual towards goal development, which serves as a critical element in acquiring hope.

Hope within the Illness Experience

Verhaeghe and colleagues (2007) explored the interface between information and hope. Analysis of interview data among family members of traumatic coma patients using a grounded theory approach revealed conceptual relationships between hope and information, with concrete, realistic hope shaped through information and its processing. Information processing was described as occurring in four steps, beginning with 1) passive absorption, which occurs when an individual first learns of the critical illness, 2) recognition of the event’s significance, which occurs as a result of seeing the ill family member, 3) seeking help from trusted others to assist with lessening the threat and facilitating reassurance and 4) learning to cope with information, which is promoted through actively obtaining and interpreting information from various sources both within and outside of the care environment. These authors note that critical care nurses are significantly positioned to provide family guidance, create strategies through which information can be interpreted and understood correctly, and foster realistic hope within the context of the illness experience.

In contrast, Morse and Penrod (1999) offer an alternate perspective, with hope emerging through acceptance, the final step in a process that begins with enduring, during which information is limited to awareness. Persons are conceiving a realistic future at the point of hope acquisition. They have become reformulated into the transcendent state, acquiring a new life perspective following a re-evaluation of priorities.
Family Emotional Reactions to Critical Illness

Overview

The need for intensive care places individuals at high risk for death, with one in five Americans dying during or soon after a critical care admission (Angus et al, 2004). Further, as many as 95% of ICU patients are incapacitated to the point of requiring surrogate decision making (Wendler & Rid, 2011; Smedira et al, 1990). These factors and others disrupt families’ emotional wellbeing, with many reporting emotional responses including stress, anxiety and depression (McAdam & Puntillo, 2009). Studies of these phenomena elucidate what is currently known about family emotional responses to a loved one’s critical illness.

Family Stress and its Risk Factors

Three different measurement tools focusing on acute (Bryant, Moulds & Guthrie, 2000), traumatic (Horowitz, Wilner & Alvarez, 1979) or overall levels of stress (Halm et al, 1993) have been employed. Family self reports of stress were noted in seven studies with sample sizes ranging from 32 to 284 family members and data collection measurement intervals that varied from 24 hours following admission to 90 days after discharge or death. Measurement tools included the Acute Stress Disorder Scale for acute stress (Cronbach alpha = 0.96), Impact of Event Scale for traumatic stress (Cronbach alpha = 0.86) and the Iowa Intensive Care Unit Family Scale for overall stress (Cronbach alpha = 0.86 for the stress scale) (McAdam & Puntillo, 2009).

Together, exploration of responses revealed elevated stress including measures of overall stress (Halm et al, 1993; Van Horn & Tesh, 2000), traumatic stress (Azoulay et al, 2005; Chui & Chan, 2007; Paparrigopoulos et al, 2006; Tilden, Tolle, Nelson & Fields, 2001) and acute stress (Auerbach et al, 2005). Results ranged from moderate to extremely high levels of post traumatic
stress (Azoulay et al, 2005). Although variable, ICU family members may experience some degree of significant stress related to their loved one’s illness.

Female gender has been proposed as a risk factor for the development of family stress (Azoulay et al, 2005; Chui & Chan, 2007; Paparrigopoulos et al, 2006). Younger family members were reportedly more vulnerable than older adults (Azoulay et al, 2005; Halm et al, 1993). Death of a loved one, participation in end of life decision making, perceptions by loved ones that they received incomplete health care information (Azoulay et al, 2005) and absence of an available advanced directive (Tilden, Tolle, Nelson & Fields, 2001) were noted as additional factors which increased family members’ risk of experiencing significant stress during the critical illness experience.

**Depression and its Risk Factors**

Five studies (Azoulay et al, 2005; Paparrigopoulos et al 2006; Pochard et al, 2001; Pochard et al, 2005; Young et al, 2005) reported depressive symptoms in samples ranging from 32 to 836 family members occurring 3 to 5 days after an ICU admission and lasting up to 3 months following ICU discharge or death (McAdam & Puntillo, 2009). Most studies employed the Hospital Anxiety and Depression Scale, which has a reported Cronbach alpha of 0.93 for the anxiety subscale and 0.90 for the depression subscale, along with documented content, construct and criterion validity (Zigmond & Snaith, 1983). Study findings revealed depressive symptoms ranging from a low of 15 % (Young et al, 2005) to a high of 35% (Pochard et al, 2001; Pochard et al, 2005). Factors associated with experiencing depression during a family member’s illness included female gender (Paparrigopoulos et al, 2006; Pochard et al, 2001); spousal critical illness, perceptions by loved ones that they received incomplete health care information and death of a loved one (Pochard et al, 2005).
Anxiety and its Risk Factors

Anxiety has been described as a response to the stress of a critical illness experience (Reider, 1994). Measurable levels of anxiety have been reported in study populations ranging from 32 to 836 participants (Azoulay et al, 2005; Delva, Vanoost, Bijttebier, Lauwers & Wilmer, 2002; Paparrigopoulos et al, 2006; Pochard et al, 2005; Reider, 1994; Young et al, 2005). Instruments used to explore this phenomenon include the Spielberger State Trait Anxiety Inventory, whose stability scores range from .16 to .62 and .65 to .86 respectively for the state and trait scales (Spielberger, 1983), the Hospital Anxiety and Depression Scale, whose psychometrics have been reported above (Zigmond & Snaith, 1983) and the Brief Symptom Inventory, whose anxiety dimension carries a Cronbach alpha of 0.81 and whose content, construct and criterion validity have been reported (Derogatis & Melisaratos, 1983).

Results revealed moderate to high degrees of anxiety ranging from 35% (Young et al, 2005) to 73% (McAdam & Puntillo, 2009; Pochard et al, 2001; Pochard et al, 2005). Risk factors for the development of anxiety included female gender and spousal critical illness (Paparrigopoulos, 2006; Pochard et al, 2001; Pochard et al, 2005). Lack of regularly scheduled family meetings with clinicians was also noted as a contributing factor (Pochard et al, 2001).

Postintensive Care Syndrome - Family

Family emotional responses to critical illness, including anxiety, acute stress disorder, posttraumatic stress, depression and/or complicated grief, have recently been encapsulated as a syndrome termed the Postintensive Care Syndrome- Family (PICS-F). In addition to the emotional responses noted above, the development of complicated grief among bereaved survivors, considered significant at the six month point and beyond, has been linked to those with PTSD (Anderson, Arnold, Angus & Bryce, 2008). Davidson, Jones and Bienvenu (2012)
comprehensively described associated PICS-F assessment and treatment mechanisms, suggesting two possible prevention strategies to include a) the way in which care providers communicate with family members and b) the inclusion of families in both care and decision making. In a related categorization of family member experiences, Baumhover and May (2013) proposed that the concept of vulnerability be extended to ICU families, noting similarities between their risks for developing poor psychologic health, poor physical health due to self neglect and poor social health due to disruptions in routines, roles and responsibilities, and similar outcomes among other populations considered to be vulnerable.

Satisfaction and the ICU Experience of a Critically Ill Family Member

Satisfaction with care is an important component of overall quality, serving as a unique construct exclusive from family perceptions of met/unmet needs (Heyland et al, 2002). Family satisfaction also serves as a barometer of provider communication effectiveness (Levin, Moreno, Silvester & Kissane, 2010). Quality care has been defined by the Institute of Medicine as care which is safe, timely, effective, efficient, equitable and patient centered (IOM, 2001). ICU families often serve as patient surrogates, requiring redirection of caregivers’ centeredness approaches from patients to family members. Studies exploring satisfaction in both ICU family members of patients who have survived and those who died have been reported, with communication and participation in decision making evolving as factors most directly related to family satisfaction (Heyland et al, 2002). Contemporary data specific to ICU families follows.

Heyland and colleagues (2002) engaged in a descriptive study of family satisfaction among 624 ICU families from six tertiary hospitals in Canada, with the goal of understanding family satisfaction differences based on site of care. Using a tool developed by Heyland & Tranmer (2001), with a reported correlation coefficient of 0.64 between satisfaction with overall care and
satisfaction with decision making and a correlation coefficient of 0.85 with overall satisfaction with care, researchers sought to correlate high satisfaction levels with key variables including overall satisfaction with the ICU experience, communication and decision making. Despite differences among institutions, the overall majority of respondents reported high levels of satisfaction with nursing skill and competence, and levels of compassion and respect provided to the patient. Pain management and care coordination received the highest scores. Items receiving the least support included the waiting room atmosphere and the frequency of physician communication. Completeness of information, respect and compassion experienced by patients/families and the amount of health care received was significantly associated with overall satisfaction. Although family member respondents were not anonymous, their willingness to report concerns regarding physician communication offered support to prior findings describing linkages between communication and family satisfaction.

Family Satisfaction and Mortality

Higher levels of family satisfaction among family members of patients who died compared to those who survived has recently been reported (Wall, Engelberg, Gries, Glavan, & Curtis, 2007). To achieve a more detailed understanding of this unexpected finding, study authors sought to explicate exact aspects using the Family Satisfaction in the ICU tool (FS-ICU), a tool based on conceptual frameworks of patient satisfaction, decision making and quality of end of life care (Heyland et al, 2002; Heyland & Tranmer, 2001) with subscales including satisfaction with care and satisfaction with decision making (Wall, Curtis, Cooke & Engelberg, 2007), and whose reliability (0.85) and validity (Cronbach alpha range: 0.74- 0.95) as a family satisfaction instrument have been demonstrated within Canadian intensive care units (Wall, Engelberg, Downey, Heyland & Curtis, 2007). Results from this second study validated initial findings of
higher overall satisfaction levels in nonsurvivor families, even after controlling for patient and family covariates (Wall et al, 2007). Examination of individual items revealed numerous statistically significant family centered care aspects including decision making inclusion, clinician communication, emotional support, respect and compassion demonstrated towards family, staff willingness to respond to questions, and concern for family needs. While fewer in number, significant patient centered aspects of care included how well nurses cared for patients and the courtesy/respect shown to the patient. These authors suggested that dying patients’ families may receive higher levels of caregiver attention, illuminating the need for universal application of family centered care practices irrespective of anticipated patient outcome.

The ICU Patient Experience with Critical Illness

Although limited in number, studies exploring the ICU patient experience serve informative data sources. Reflected in these studies is a need for further attention to the patient’s lived experiences. Findings include experiences during which patients perceive a loss of personal dignity, while others consider the ICU an embodiment of safety promoted by technologic supports and human compassion. A review of the extant literature follows.

Physical symptoms experienced by critically ill patients at high risk of dying have recently been explored by Puntillo and colleagues (2010). Symptom presence and intensity were assessed using a ten item symptom checklist developed by the study’s authors. The instrument, which was created following a thorough literature review of symptom assessment tools, achieved both face validity and 100% interrater reliability. Prevalence of physical symptoms ranged from a high rate of fatigue (75%) to lesser experiences of confusion (27%). Patients described a thirst experience that was moderately intense, while other symptoms including shortness of breath, fear, confusion and pain were reported as moderately distressing.
Russell (1999) explored memories of ICU experiences in a sample of 298 former patients using either self-reported questionnaires or structured interviews. Although 34% reported no memory of the ICU, the remaining participants had either some memory or very clear recollection of their ICU experience. These memories were categorized as 1) care by ICU health practitioners 2) technologic ICU support 3) visitation by relatives 4) procedures and treatments 5) ICU noise 6) other ICU patients 7) feelings of safety 8) fear 9) people everywhere and 10) lack of personal control. Although interpretations varied widely, with some perceiving the environment and its tools as a reflection of safety while others experienced a deleterious psychologic impact perhaps related to real or distorted memories of pain, upsetting dreams, noise, fear or lack of privacy, it was the human interaction displayed when reassurances were communicated and attention provided that offered an emotional safety net.

**ICU Patient Stressors**

Fredriksen and Ringsberg (2007) described types of ICU patient stressors. Reported patient stressors included bodily reactions such as sweating, tachycardia, hyperventilation, restlessness and insomnia; situational experiences including pain and fear; emotional responses directed towards the integration of person with requisite technical equipment and procedures; and stress resulting from a loss of meaning. The ICU room was described as a stressor emerging from simultaneous existences of being alive and being seriously ill, with the physical environment serving as reaffirmation of the lived experience of a critical illness. Disturbances in human relationships between self, significant others, nurses and physicians further illustrated sources of ICU stressors.

An existential analysis of experiences and their relationship to stress was undertaken using a phenomenological-hermeneutical approach. Physiologic responses, described as bodily reactions,
reflected expansion from having a body to being a body, were cognitively perceived as abnormal, and led to a stress response (Benner and Wrubel, 2001; Fredriksen and Ringsberg, 2007). Stress was reportedly generated when the body realized that ICU procedures, noise and care activities prevented its ability to sleep, the rest component of the body’s activity/rest pattern, causing insomnia-related limitations in self-healing functions. Fear and pain influenced both bodily functions and the entire self, resulting in stress. Similar to Russell’s (1999) findings, patients in this review either embraced technical equipment and procedures as symbols of hope and life or, alternatively, developed a stress response driven by fear of being attached to technological supports. Human capacity to understand and rationally adjust to situations allowed for formulation of meaning. However, when this human capacity was missing, stress resulted from the overwhelming human experience of loss of meaning.

Persons typically interact with their environment and significant others in ways reflective of their individuality. The ICU environment is controlled by others. Environmental characteristics such as lighting and temperature, and provider interventions performed for the patient, exemplify potential sources of stress due to patient powerlessness and lack of control. Words and actions serve as mechanisms through which the self is expressed but, when repressed by critical illness, helplessness and stress may ensue, demonstrating again the importance of relationship in engendering a sense of patient safety and hope.

Patients’ Emotional Safety

With concerns about ICU patients’ psychosocial status gaining literature attention, including the revelation of accurate memories and the stressors imposed by a critical care experience, Hupcey (2000) engaged in a qualitative study to more fully explore this phenomenon. Patient psychosocial needs were explored using a grounded theory methodology. The study population included
medical and surgical ICU patients receiving care in a rural, tertiary medical center in the eastern United States, with a length of stay that ranged from 3 days to more than one month.

Hupcey (2000) described a model illuminating safety as the core variable associated with patients’ psychosocial needs, with additional categories of knowing, regaining control, hoping and trusting serving as the affecters for safety achievement. Both perceptions about safety and the associated categories noted above were discovered to be influenced by family/friends, ICU staff, and spirituality. According to the proposed model, critically ill patients have safety needs meet through stimuli provided by these influencing factors. Additionally, families, friends and ICU staff served a supportive role by watching over the patient and being present, and patients achieved similar feelings of comfort knowing that they were being watched over by a spiritual source.

Family/friends, ICU staff and a spiritual connection were found to formulate linkages between the ICU experience and feelings of safety within the experience. Knowing related specifically to an understanding of what was happening, and was promoted through information provided by family/friends and the clinical staff. Regaining control represented a turning point from an initial perception of total loss of control, and may be related to control over visitors, mobility or other aspects of realization associated with one’s status as an ICU patient. According to one patient report:

I don’t have any freedom. I’m confined to bed and the kids can only come in for 10 minutes at a time every hour so it’s hard on them because 10 minutes is hardly worth the effort of coming in. So it’s uncomfortable for them and it’s very uncomfortable for me (p. 5).

Hope kept patients from giving up, and was fostered both internally and externally by the encouragement of family, friends, ICU staff and religious perspectives. Patients often reported that encouragements connecting them to their outside world, such as to family and events, served as supportive mechanisms by which hope was facilitated. Trust, the fourth category affecting
patients’ safety, was deemed essential and was recognized from its implicit nature, with patients only discussing this concept when they felt the absence of the phenomena and the associated lack of perceived safety.

**Meaning of Social Support**

Recognizing the importance of social support, both from family/friends and ICU staff (Geary, Formella & Tringali, 1994; Geary, Tringali & George, 1997; Hupcey, 2000), Hupcey (2001) proceeded to explore the meaning of social support for critically ill patients. The experiences of thirty critically ill patients ranging in age from 31 to 72 with various clinical problems including cardiovascular, pulmonary, oncologic and endocrine disorders were studied using a descriptive qualitative methodology. Themes from the data analysis revealed: a) the need for social support, b) the quality of this support and c) lack of social support and its impact.

Social support was characterized as being directly related to illness acuity. During periods of high acuity, social support was deemed necessary by patients, but they requested the presence of only one or two individuals with whom they had a significant relationship. As clinical stability was achieved, patients were willing to expand the scope of desired visitors to include other family and acquaintances. The total number of visitors and perceptions of social support were not directly related, as some experienced tremendous support from a small cadre of persons while others perceived an absence of support despite large numbers of visitors, suggesting the importance of quality within social support mechanisms. As observers to the process, nurses believed patients receiving high levels of social support were those who had the largest number of calls of visitors.

The quality of interaction influenced the meaning of social support, with close family members being desired during the most critical period due to the level of comfort felt when having a close person at one’s side. Behaviors served as a measure of patients’ perceptions of the quality of
interactions. Positive behaviors were manifested as an upbeat approach, rallying around the patient, serving as a person on whom the patient could depend and offering assurances that concerned others were providing support through prayer. Social support interactions deemed to be of poor quality or nonexistent resulted in negative perceptions of the hospitalization experience. Accordingly, patients offered disapproving appraisal of the staff, the care provided, and support from family or friends.

Challenges to Nursing Engagement with ICU Patients and Families

Critical care units were developed to integrate high levels of medical and technical support with intensive nursing care in the battle against patient death (Liaschenko, O’Connor-Von & Peden-McAlpine, 2009). Although the nursing discipline is recognized for its holistic care approach, holism is often superseded by ICU nurses’ moment to moment management of physiologic parameters. Despite acknowledgement of cognitive and emotional family needs (Molter, 1979), nursing has not achieved full engagement with ICU families, demonstrating inconsistencies and variability within disciplinary practice. Reasons for critical care nursing’s incomplete attention to holism are multifactorial.

Plowright (1998) engaged in a descriptive survey methodology to assess nurses’ perspectives on family visiting. Negative beliefs within this sample of 68 nurses focused on proximity, space and time, with nurses reporting instances of families obstructing care activities, especially in units with limited space, and family engagement of nursing time, presumably sequestering time that could be devoted to patients. In addition, issues of power and control were discovered, with nurses restricting visitors even in units with open visiting policies. Reasons for doing so included the perceived critical nature of the patient’s illness, the need for patient rest, physician rounds or as a mechanism to restrict those considered unpleasant. Interestingly, this author found that more
experienced nurses were attuned to the physiologic and psychologic benefits promoted by visiting. In related work, Benner, Tanner and Chesla (1996) noted the impact of nursing experience on visiting, with less experienced nurses reporting feelings of incompetence when faced with the psychosocial needs of patients and families, especially in clinically complex situations.

Nurse/family Interaction and Responsiveness

Factors associated with nurses’ responses to family needs were assessed by O’Malley (1991) through use of a survey instrument adapted from Molter’s Critical Care Family Needs Instrument (1979) to determine the nurse’s perception of a need’s importance, time available for the nurse to attend to a need, the environment of care and the nurse’s ability to meet a need. Attitudinal factors included the time required to accomplish the task, perceived stress level, knowledge of family crisis management style and the nurse’s role security. Similarly, Chesla (1996) discovered considerable variation in nurses’ provision of family care, with some providing only clinical patient management at the exclusion of the family, while others demonstrated expert family attention integrated with excellent care of the complex, critically ill patient. Distancing strategies similar to those found in Chesla’s study were also reported in a qualitative study by Hupcey (1998). Using grounded theory, interview data from ten ICU family members and ten nurses practicing in a large rural teaching medical center was assessed. Isolation practices included limitations of family visiting, providing only superficial responses to family questions, depersonalization of the patient and family, and maintenance of an attitude of efficiency. Nurses demonstrating a willingness to engage did so by expressing commitment to and involvement with families (Hupcey, 1998).
Patient and Family Centered Palliative ICU Care

Care focused at end of life began more than 30 years ago as the home hospice movement (Ferrell et al, 2007). Contemporary applications have recently evolved to include palliative care models serving a variety of care settings. Palliative care is now described as an encompassing model of care focused on symptom reduction, communication support for patients, loved ones and care providers, and care continuity across patient settings.

Palliative care is considered both a philosophy of care and a system of structured care delivery serving patients and families experiencing serious life-threatening illnesses (National Consensus Project for Quality Palliative Care, 2004). It offers an interdisciplinary approach focused on the management of physical, psychological, spiritual and practical burdens of illness. Core elements and clinical practice guidelines were described in the 2004 National Consensus Project document (Table 2-1), and subsequent advancement within the field occurred when the National Quality Forum released an accompanying document outlining preferred practices for palliative care (Ferrell et al, 2007).

Quality Indicators

Life preserving ICU care results in palliative patient and family needs. Patients experience high acuity illnesses with accompanying symptoms of distress; their loved ones require clear and accurate communication from care team members; and the possibility of a prolonged hospitalization portends numerous care unit transitions. Yet, until recently, evidence revealed a lack of organized clinical approaches to these needs (Levy & McBride, 2006), including inadequate symptom control at end of life (Desbiens et al, 1996) and communication difficulties between families and providers (Curtis, Patrick, Shannon, Treece & Engelberg, 2001). Recent forward momentum occurred when The Robert Wood Johnson Foundation published a consensus
document outlining domains of quality indicators in palliative and end of life ICU care to include patient/family centered decision making, communication within the team and with patients/families, continuity of care, emotional/practical support for families, symptom management and comfort care, spiritual support of patients/families and emotional and organizational support for ICU clinicians (Clarke et al., 2003).

Contemporary confirmatory studies validate many of these domains. Nelson and colleagues (2010 b) employed a focus group methodology to ascertain perceptions of high quality palliative care among critically ill patients and families. Respondents noted the need for timely, clear and compassionate clinician communication; the importance of invoking patients’ preferences, goals and values within clinical decision making processes; patient care focused on comfort, dignity and personhood; family care composed of open access and proximity; interdisciplinary support; and bereavement care.

Family Symptoms

Symptoms experienced by families reveal the importance of family centered ICU care, including open access, proximity and interdisciplinary support. A recent study exploring family emotional responses among three ICUs within a west coast university hospital reported levels of traumatic stress, anxiety and depression ranging from 57 to 80 % (McAdam, Dracup, White, Fontaine & Puntillo, 2010). Instruments employed and their reported reliability measures within the study included the Impact of event Scale – Revised to measure traumatic stress (Cronbach alpha 0.93), Hospital Anxiety and Depression Scale to measure anxiety and depression (Cronbach alpha 0.87 for anxiety and 0.73 for depression, Edmonton Symptom Assessment Sale – Revised to measure symptoms such as pain, sadness and fear (Cronbach alpha 0.82), Family Crisis-Oriented Personal Scales to measure family coping (Cronbach alpha 0.80), and the Family Adaptability and
Cohesion Evaluation Scale to measure family functioning (Cronbach alpha 0.78). Families in this study also reported the development of moderate to severe levels of fatigue, sadness and fear.

Palliative Care Access

Initiatives aimed at increasing palliative care access in the ICU are being reported (Nelson et al, 2010a). Two main structures have been used to facilitate these outcomes including the consultative model, identified as a mechanism by which the ICU staff invites consultation from palliative care experts, and the integrative model, defined as the expansion of ICU care team expertise to include palliative care principles. In addition, a third hybrid model comprised of the development of palliative care expertise within the ICU care team supplemented by external palliative care consultation has been reported (Billings & Keeley, 2006; Nelson et al, 2010a).

Supportive Family Care in the Patient Centered ICU

Few comprehensive guidelines for family support are available. One contemporary example has been reported by Davidson et al (2007). This specific work and related information follow.

Evidence based recommendations addressing family support mechanisms within adult, pediatric and neonatal ICUs have been offered by the American College of Critical Care Medicine (Davidson et al, 2007). This encompassing document (Table 2-2) contains guidelines specific to decision making, family coping, staff stress associated with family interactions, family cultural support, spiritual/religious support, family visitation, family environment of care, family presence on rounds, family presence during resuscitation and palliative care. Developed with a goal of supporting patient centeredness within the ICU, these guidelines were formulated with an appreciation of the proxy role served by loved ones of ICU patients, the complexities of participation within such a role and the need to successfully address patient/family centeredness using a patient, family and multiprofessional clinical team model of shared decision making.
Patient/Family/Provider Shared Decision Making

Endorsement of an integrated shared decision making approach within end of life care was previously established by the 5th International Consensus Conference in ICU End of Life Care, during which time it was further defined as a dynamic decision making model involving patient surrogates and clinicians with the intended goal of achieving consensus on end of life processes while accommodating patient values within a context of emotional support (Carlet et al, 2004). As an intervention for patient/family support for all ICU patients, shared decision making is proposed due to its substitution of exclusivity in decision making with involvement of all participants through the formulation of a patient/family/clinician partnership. In addition to a process of partnered decision making, Davidson and colleagues (2007) suggest that providers fully disclose patient status, prognosis and reasonable management options; seek to understand the level of life sustaining therapies desired; establish family/team meetings within 24-48 hours of admission and on an ongoing basis as necessary; and engage in communication, conflict management and meeting facilitation training programs.

Family Coping and the ICU Experience

As noted previously, families and others may experience emotional symptoms (McAdam & Puntillo, 2009), as well as dissatisfaction with provider communication (Curtis, 2008) during the ICU care experience. Family responses to this intense time have been well articulated. Recommendations (Davidson et al, 2007) for supportive ICU environments that enhance individual coping mechanisms have been outlined to include staff training in family needs assessment, including assessment of stress and anxiety; care provider consistency to minimize the number of providers with whom patients and families interact; involvement of family in the
provision of care; and creation of family support strategies by an ICU team of multidisciplinary professionals.

**Staff Member Stress Related to Family Interactions**

Patient centered environments are optimized using a multiprofessional approach, yet this approach requires the use of collaborative dialogue to foster consensus regarding plans and goals. Inherent within this approach is the necessity for clear lines of communication among care providers and between providers and patients/families. As a result, it is suggested (Davidson et al, 2007) that the treatment team develop and share uniform and clear goals to achieve diminution of provider/family friction, and establish mechanisms by which staffs are empowered to request debriefings addressing care plan concerns, the need to decompress, vent feelings or grieve experiences.

**Cultural Family Support**

Cultural diversity within the ICU influences the tenor of care. Described as a pattern of learned beliefs, values and behavior, culture is inclusive of language, communication styles, practices, customs and perceptions regarding roles and relationships. Culture and ethnicity serve as important filters through which both communication and ethical principles are interpreted. Harmonization between provider and patient/family culture is encouraged, as is provider education specific to culturally competent care, and care delivery which is aligned with the patient/family cultural norms (Davidson et al, 2007).

**Spiritual/Religious Support**

While few studies have assessed the connection between spirituality and critical illness, there is thought to be a need for further exploration of spirituality among those experiencing a life threatening illness, with the interdisciplinary team assuring sensitivity towards the interface of
spirituality and critical illness. Suggested mechanisms by which this can be accomplished include assessment of spiritual needs and their incorporation into the plan of care; physician acknowledgement of and attention to spiritual assessment data provided by other providers including chaplains, social workers and nurses; spiritual training for physicians and nurses; and honoring of patient/family requests for inclusion of prayer into the care environment (Davidson et al, 2007).

Family Visitation

Despite decades of studies validating the ICU family’s need for proximity to loved ones, families have been often marginalized within the ICU care environment. Strict visiting policies have kept families on the periphery, as has practitioner nonadherence to more liberal policies. An open visiting approach demonstrating clinician flexibility towards individual patient/family needs and consideration of pet therapy and visitation is recommended (Davidson et al, 2007).

Family Environment of Care

The ICU environment, including color, lighting, and sound are modifiable components of patient/family care. Provision of privacy within the ICU environment has been found to impact patient/family willingness to engage in highly intense conversations often associated with an ICU admission, as well as family provision of personal care to loved ones. Private ICU rooms which incorporate family space and adequate way-finding systems, as well as further scientific exploration of the impact design elements have on ICU families are recommended (Davidson et al, 2007).

Family Presence during Resuscitation

Family presence during resuscitation is most commonly described in relation to emergency and pediatric practice environments. Family presence has been recommended by various national
organizations, including the American Heart Association (AHA, 2005). Despite these endorsements, support for ICU family presence tends to be more prevalent within nursing than physician practice. Implementation of a carefully structured process allowing family member presence during cardiopulmonary resuscitation is recommended, including involvement in post resuscitation staff debriefing; team membership formulated to include one individual designated for provision of family support during presencing; and team training includes education specific to family presence (Davidson et al, 2007).

**Palliative Care**

Families often identify signs of patient suffering during their loved one’s critical illness (Billings, 2000; Davidson et al, 2007; Faber-Langendoen & Lanken, 2001; Patrick, Engelberg & Curtis, 2001; Teno, et al, 2004). Palliative care provides supportive services to help relieve suffering, with key aspects including symptom control, psychosocial and spiritual care, quality of life planning and family support. Interventions ranging from invasive procedures to patient repositioning invoke potential discomfort and highlight the importance of critical care and palliative care integration (Davidson, et al, 2007; Maclean, et al, 2003). Few multidisciplinary providers have been educated to address end of life within the ICU. As a result, formal integration of palliative care within critical care education, including assessment of family understanding of their loved one’s illness and its likely sequela of symptoms, side effects, functional limitations, treatments and the family’s coping capacity regarding the actual illness and its subsequent consequences; provision of culturally sensitive information specific to evidence of impending death and opportunities for participation in hospice palliative care; and sharing information about available bereavement or follow up care opportunities are all suggested (Davidson et al, 2007).
Family Interventions: Theory Development

A theoretically based synthesis of nursing interventions for family member care has recently been proposed (Davidson, 2010). Entitled facilitated sensemaking, this middle range nursing theory is based on the proposition that ICU families need to both make sense of the critical illness experience in which they find themselves, and to assimilate care giving into this experience. A set of specific nursing interventions are suggested to assist family achievement of both outcomes, with the overarching primary goal of preventing adverse psychological outcomes by supporting family members’ emotional health and adaptation. Nursing interventions focused on the sensemaking aspect include interpretation of the patient’s clinical presentation for family members, and use of reflective inquiry prior to the family member’s departure to clarify any misconceptions that may have emerged. Further, involvement in bedside activities may help with family member adaptation. Together, these nursing interventions may support families’ emotional integrity by reducing or preventing fear, horror and helplessness.

Family Interventions: Empiric Findings

Recognition of the importance of information within the ICU family experience coupled with interest in studying effective mechanisms of family communication led to quality assessments of family support and engagement in shared decision making processes (Lautrette, Ciroldi, Ksibi & Azoulay, 2006). Further, in addition to these associated quality measures, and in response to the acknowledged expansion of health care interventions at end of life, resource utilization has surfaced as an additional end point in the measurement of ICU family communication. Select studies representing family intervention data will be reviewed.
Team-Family Communication

Azoulay and colleagues (2002) assessed the impact of an informational brochure on family comprehension of diagnosis, prognosis, treatment and satisfaction with information provided by ICU caregivers. Using a multicenter, prospective, randomized, controlled design, 87 of 175 families were provided with standard information supplemented by the information brochure. Families who received a brochure containing general ICU information, the physician’s name, a diagram of an ICU room including names of the devices and a glossary of 12 commonly used ICU terms demonstrated statistically significant improvements in comprehension and satisfaction, suggesting derived benefit from structured provision of information.

The effect of team/family communication coupled with provision of a written brochure on family emotional symptoms was reported by Lautrette and colleagues (2007). Families of ICU patients with a high likelihood of death were randomly assigned to either standard care or the interventional approach which, in addition to the above components, provided families more opportunity to speak during team meetings. Study evidence revealed statistically significant lower levels of PTSD, anxiety and depression in the intervention group.

Using a pre/post research design, Lily and colleagues (2000) assessed the impact of an early, intensive, multidisciplinary team/patient/family communication strategy designed to establish clinical goals and their associated time frames. The intervention was coupled with the introduction of palliative care for those in whom death was likely. Results demonstrated a reduction in median ICU length of stay from 4 to 3 days in the targeted group of high acuity patients with a strong likelihood of death. Importantly, there were no mortality increases as a result of the intervention. These authors suggest the use of intensive, collaborative, goal directed communication as an effective intervention that could also favorably impact the cost of ICU care.
A physician/clinical nurse specialist model of communication designed to allow families time
to process information as their loved one approached end of life, and its impact on the integration
of goals of care, cost and care provision has been reported (Ahrens, Yancey & Kollef, 2003).
During a one year period, 43 of 151 eligible families of patients nearing death participated in a
quality improvement intervention, which included both physician-provided medical updates and
daily clinical nurse specialist information sharing coupled with an opportunity for family
processing. Significant results were demonstrated in the intervention group compared to those
receiving standard of care, resulting in shorter ICU and hospital lengths of stay along with lower
fixed and variable costs.
Patient Diaries

Diaries represent a contemporary nursing intervention directed towards enhancing factual recall
among ICU patients, who are often either unable to recall their critical care experiences, or have
frighteningly distorted recollections. Intuitively employed by Danish nurses to assist patients with
their emotional recovery following an ICU stay, they then proliferated among other Scandinavian
countries, acquiring recognition through evaluations of patients’ experiences and of diary use
(Egerod, Storli & Akerman, 2011). Recent empiric assessment of their efficacy using both the
Hospital Anxiety and Depression Scale (Cronbach alpha = 0.87 for anxiety and 0.73 for
depression) as measures of anxiety and depression and the SF-36 as a measure of health related
quality of life, has led to an appreciation of their capacity to reduce ICU patient anxiety and
depression (Knowles & Tarrier, 2009) and to enhance health related quality of life (Backman,
Orwelius, Sjoberg, Fredrikson & Walther, 2010). Reductions in post traumatic stress using the
Impact of Events Scale, a reliable and valid measure of subjective stress, have been noted among
both patients (Jones et al, 2010) and family members (Garrouste-Orgeas et al, 2012).
Nursing Knowledge Development and Human Experience with Critical Illness

Qualitative inquiry into human experiences has contributed to nursing knowledge development through discoveries which illuminate understanding of individual and group phenomena throughout the life span. Categorization of knowledge derived from studies employing the HEC praxis methodology include information about 1) life patterning within shared predicaments, 2) evolving nurse-client relationships, 3) processes of HEC practice implementation and 4) discovery of community patterns and their capacity to serve as change agents (Smith, 2011). An overview of studies within these categories follows.

Life Patterning Within Shared Life Predicaments

Studies among these individuals focus on the experience of diseases and challenging situations. Diseases of inquiry include breast cancer, coronary heart disease (CHD), HIV/AIDS, cancer, chronic obstructive pulmonary disease (COPD) and chronic illnesses (rheumatoid arthritis, multiple sclerosis and skin wounds). Women described elements of health within their lived experiences of breast cancer as acquiring information and making choices, finding meaning and discovering new ways of living and being (Moch, 1990). Patterning among patients with CHD demonstrated their need to excel and please others, accompanied by concomitant feelings of aloneness (Newman and Moch, 1991). Men with HIV/AIDS revealed a pattern consisting of struggle, aloneness and alienation, which then evolved into personal growth driven by experiences of illness suffering (Lamendola and Newman, 1994). An additional HEC praxis study of men with HIV/AIDS (Awa and Yamashita, 2008) found similar patterns, with the choice point experience of personal growth leading to enhanced compassion and connectedness. Patterning among individuals with cancer exposed a history of childhood deprivation and a lack of connectedness which, for some, was able to evolve into a more authentic life (Newman, 1995). Persons with COPD
exhibited pattern similarity including isolation and feelings of being closed in (Jonsdottir, 1998). Rosa (2006) described pattern recognition among persons with chronic skin wounds as a healing process which led to new awareness, change and life integration of the wound experience.

Challenging situations reflect another category of life predicament, including childhood cancer survivors, family caregivers for persons with mental illness, incarcerated adolescent males, women who maintained significant weight loss, women experiencing menopause and nicotine abusing college students. The work of Karlan, Jankowski and Beal (1998) revealed transformative experiences among childhood cancer survivors that patterned into hope and optimism, family bonds, greater empathy, desire to help others and appreciation for life. Family caregivers of individuals with schizophrenia noted struggling as their predominant pattern, with some able to transform through use of the praxis methodology (Yamashita, 1999). Pharris’ exploration of pattern in young men convicted of murder (2002) revealed the impact of severed relationships and the absence of community support on their eventual transition into a world of violence. Most of these individuals were emotionally engaged while participating in and recognizing the pattern that led to their crimes, and they subsequently revealed transformative capacity through their desire to achieve meaning during their incarceration. Women who maintained significant weight loss transformed emotionally to higher levels of awareness, confidence and self esteem (Berry, 2004). Women transitioning through menopause demonstrated similarities in pattern such as coming to terms with losses and unexpected gains, and a concentration on health and vitality (Musker, 2008). Pattern similarity among nicotine abusing college students highlighted difficulties within an important relationship, with smoking serving as a mechanism through which the students could connect with others (Endo, Takaki, Natsuko, Abe & Terashima, 2009).
Evolving Nurse-Client Relationships

Exploration through nurse-client partnerships led to pattern recognition, emotional growth and an appreciation of profound meaning among ten women with ovarian cancer (Endo, 1998). In a subsequent study, Endo et al (2000) explored family patterning in the family-nurse relationship among Japanese families experiencing ovarian cancer. Family participants revealed growth in their caring relationships, including increased openness, connectedness and trustfulness, which fostered a transformation from their separate, individual experiences to engagement and development of trustful, caring family relationships. Pattern recognition among families with a special needs child was explored by Falkenstern, Gueldner and Newman (2009). Family participants and nurses engaged in a transformative process revealing multiple dimensions including freedom for limitless expression, a feeling of timelessness for awareness and insights and resonating with each other as one for transformation. Families reported experiences of enhanced acceptance of their child’s limitations, confidence with parenting decisions, the capacity to appreciate how their actions were impacting their child, and development of trust and respect within the family unit.

Process of Implementing HEC in Practice

Nurses practicing on a 48 bed Japanese cancer unit implemented HEC among select patients referred to them due to colleagues’ perceptions that they were experiencing “difficulties”. These nurses developed a distinct appreciation for the nurse-client relationship and its co-creation of meaning through recognition of its impact on facilitating both the client’s transformation and that of their own (Endo, Miyahara, Suzuki & Ohmasa, 2005). A pre-operative setting whose structure incorporated HEC illuminated transformative practice for both patients and nurses (Flanagan, 2009).
These practice examples provide a view into human capacity for transformation from self identity to the development of new ways of being, freedom and consciousness within the illness experience. Disease is a message (Newman, 2008) to which a listening ear discovers understanding beyond the superficial. Focusing on persons through engagement within nurse/client relationships provides awareness of disease as an integrating factor (Newman, 2008), fostering human evolution through pattern recognition. Disease can be seen as an advocate, moving persons to accomplishments they were previously unable to achieve (Newman, 2008).

Community Pattern Recognition as a Catalyst for Change

Community supports were implemented following community member/researcher dialogues illuminating opportunities for engagement and support of youth at risk for violent crimes; these recommendations emanated from the researcher’s study employing HEC praxis with young men incarcerated for murder (Pharris, 2002). HEC praxis was again chosen as this author’s methodology to study health disparities among multicultural women and girls (Pharris, 2005). Findings, which revealed racism as the most prominent factor in the creation of disparate health, were shared via a multimedia approach including meetings, television and DVD. Pattern exploration among immigrant diabetic Hmong American women led to an appreciation of their perceptions linking diabetes with experiences of alienation, displacement and devaluation within a foreign land. These issues were also shared within the community employing a multimedia approach (Yang, Xiong, Vang & Pharris, 2009).

Summary

Scientific explorations focusing mostly on reductionist and cause-effect philosophic paradigms have been employed in an attempt to explicate greater understanding of the family experience during a loved one’s critical illness. While clarity regarding the family’s risk for developing
deleterious emotional reactions has emerged, detailed understanding of risk factors is limited. Contributing to this is a paucity of information about the application of measurement tools and specifics of their requisite populations, including illness trajectory, relationships between loved ones and the critically ill individual and family member pre existing emotional states, as well as relationships between these and other contributing factors.

Confusion about symptom ameliorating interventions also exists. Family members clearly indicate the importance of hope, but qualitative explorations lend uncertainty to the timing of hope inspiring nursing interventions such as information sharing. Some researchers have suggested that information provided early in the illness trajectory is absorbed and quickly integrated into a hopeful future, while others have noted an initial response of endurance, during which information is acknowledged only as awareness, with the formulation of hope occurring in the more distant future. Empiric clarification is necessary for the provision of appropriately timed evidence based nursing interventions.

Studies within the theoretical boundaries of the unitary transformative paradigm employing Newman’s Health as Expanding Consciousness theory revealed the capacity of pattern recognition within an integrated person/environmental field to aid knowledge development. Further, emergence of human flourishing within the illness experience was fostered through development of insight and personal action. The experience of physical illness advanced personal understanding of oneself to achievement of new levels of consciousness. Clarity of outcomes with this holistic approach suggests its value within the critical care family/registered nurse interface.
Table 2-1

*National Consensus Project Core Elements of Palliative Care*

<table>
<thead>
<tr>
<th>Element</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Population</td>
<td>Patients of all ages experiencing a debilitating chronic or life-threatening illness</td>
</tr>
<tr>
<td>Patient and Family Centered Care</td>
<td>The unit of care is constituted by patients and their families/loved ones. Their unique nature is determined through their expressed goals and preferences</td>
</tr>
<tr>
<td>Timing of Palliative Care</td>
<td>Begins at the time of diagnosis and continues through cure or death, and into the loved ones’ bereavement period</td>
</tr>
<tr>
<td>Comprehensive Care</td>
<td>Ongoing multidimensional assessment to determine appropriate interventions for physical, psychological, social and/or spiritual distress</td>
</tr>
<tr>
<td>Interdisciplinary Team</td>
<td>A core professional group from medicine, nursing social work, expanded as necessary to address needed services</td>
</tr>
<tr>
<td>Attention to Relief of Suffering</td>
<td>Prevention and relieve of the various burdens imposed by both the disease and its treatments, including pain and other symptom distress</td>
</tr>
<tr>
<td>Communication Skills</td>
<td>Developmentally appropriate and effective sharing of information, active listening, determination of goals and preferences, assistance with medical decision-making, and effective communication with those involved in patient and family care</td>
</tr>
<tr>
<td>Skill in the Care of the Dying and the Bereaved</td>
<td>Knowledge required in prognostication, signs and symptoms of imminent death, and associated care and support needs of patients and loved ones, including age specific syndromes, opportunities for growth, normal and aberrant grief and bereavement processes</td>
</tr>
<tr>
<td>Continuity of Care Across Settings</td>
<td>Assurance of coordination, communication, and continuity across institutional and home care settings, with the goal of preventing crises and unnecessary transfers</td>
</tr>
<tr>
<td>Equitable Access</td>
<td>Equal access for all patients and families irrespective of age, patient population, diagnostic category or health care setting</td>
</tr>
<tr>
<td>Addressing Regulatory Barriers</td>
<td>Concerns about drug misuse should not interfere with the use of opioid analgesics for</td>
</tr>
<tr>
<td>Quality Improvement</td>
<td>Validated instruments employed to systematically measure care processes and outcomes data</td>
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Table 2-2

**ACCCM Family Support Guidelines**

<table>
<thead>
<tr>
<th>Concept</th>
<th>Recommendations</th>
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</table>
| Decision Making                  | 1. Decision making is based on a partnership between the patient/surrogate and multiprofessional team  
2. Clinicians will disclose the patient’s current status and prognosis, and explain all reasonable management options  
3. ICU clinicians strive to understand the level of desired life sustaining therapies  
4. Family meetings with the multiprofessional team are initiated within 24-48 hours of admission and are repeated as clinical indicated  
5. ICU caregivers receive training in communication, conflict management and meeting facilitation skills |
| Family Coping                    | 1. ICU staff receive training on how to assess family needs, stress and anxiety levels  
2. Consistency is maintained in the assignment of physician and nursing staff  
3. Families are encouraged to participate in care activities  
4. Families are informed about emotional needs of patients and methods of providing emotional support  
5. Family support is provided by the multiprofessional team |
| Staff Stress related to Family Interactions | 1. Treatment goals are shared among the multiprofessional team to foster consistency of information sharing and reduction of friction among team members, and between the team and family  
2. A mechanism exists to allow any staff member to request a debriefing to voice concerns with the treatment plan, decompress, vent feelings or grieve |
| Cultural Family Support          | 1. Matching of provider culture with patient culture occurs upon request or when cultural value differences lead to conflict  
2. Healthcare professionals are educated |
3. The patient is assessed for his/her desire to be told the truth
4. When conflict about truth telling emerges among patients and families, the patient’s wishes take precedence
5. Cultural norms are considered and respected when procedural assent is sought
6. Respect is shown to patients’ “informed refusal” of information

**Spiritual/Religious Support**

1. Spiritual needs are assessed, and findings related to health and healing are incorporated into the plan of care
2. Physicians will review ancillary team members notes (chaplains, social workers, nurses) and integrate their findings into the plan of care
3. Nurses and physicians are trained in spiritual awareness and religion to both assist with patient care and better understand the contributions of chaplains and social workers
4. Healthcare workers will honor a patient request for prayer if comfortable doing so

**Family Visitation**

1. Open visitation in the adult ICU promotes flexibility and is determined individually
2. The visitation schedule is collectively determined among the patient, family and nurse
3. PICU and NICU visitation occurs 24 hours a day
4. Sibling visitation in the PICU and NICU is allowed following both parental approval and participation in a previsit educational program; caution is advised for immunocompromised infants
5. Clean and properly immunized pets may be considered for visitation; animal assisted therapy guidelines should be developed

**Family Environment of Care**

1. ICU rooms should be designed as single rooms with family space to promote patient confidentiality, privacy and social support
2. Reduce stress through the use of signs and way-finding systems
<table>
<thead>
<tr>
<th>Family Presence on Rounds</th>
<th>3. Replicate research focused on the relationship between the patient and room environment to include families</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1. Parents or guardians are provided the opportunity to participate in ICU rounds</td>
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<td></td>
<td>2. Adult patients or those serving as proxy are afforded the opportunity to participate in rounds</td>
</tr>
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<td></td>
<td>3. Pediatric patients are allowed to participate in rounds following parental permission</td>
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<td></td>
<td>4. Patients and family members are provided the opportunity to ask questions during rounds</td>
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<table>
<thead>
<tr>
<th>Family Presence at Resuscitation</th>
<th>1. Develop a structured process allowing family member presence during resuscitation, including staff debriefing</th>
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<tr>
<td></td>
<td>2. The resuscitation team includes a designated member trained to provide family support during witnessed resuscitation</td>
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<tr>
<td></td>
<td>3. Family presence information is included in staff resuscitation training</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Palliative Care</th>
<th>1. Family assessment includes their understanding of and responses to illness. Family education is based on these results.</th>
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<tbody>
<tr>
<td></td>
<td>2. Family education includes signs and symptoms of impending death, based on cultural and developmental needs</td>
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<tr>
<td></td>
<td>3. Information is provided about the availability of community based resources, including hospice palliative care</td>
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<tr>
<td></td>
<td>4. Bereavement services and follow up care are available</td>
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<tr>
<td></td>
<td>5. Palliative care training is included in critical care education</td>
</tr>
</tbody>
</table>

CHAPTER THREE

Introduction

This chapter addresses study design and associated methods, including study purpose, research questions, sample and setting, protection of human subject rights, data collection, data analysis, rigor and validity. The study purpose is to employ the hermeneutic phenomenological approach of the HEC praxis methodology to explore care experiences within the ICU. The following research questions will be addressed.

1. What is the family experience of relationship based care when a critically ill loved one is receiving care within a medical intensive care unit environment?

2. What experiences are revealed by nurses practicing within a relationship based practice model when caring for families in a medical intensive care unit environment?

Design

*Phenomenology*

The study’s research questions were answered using qualitative research, which is defined as the investigation of phenomena. Phenomenology serves as one qualitative method designed to explore the lived experiences of humans (Polit & Beck, 2008), as it promotes the unfolding of individuals’ experiences of meaning as they participate with others within their situated environments. Attention to meaning and relationship aligns this methodology with nursing’s disciplinary goals (Lopez & Willis, 2004). Two phenomenologic approaches have been identified, including descriptive/eidetic and interpretive/hermeneutic (Cohen & Omery, 1994).

Research exploring the lived experience of being human requires both a philosophical foundation and its associated research methodology. Traditionally, phenomenology has provided philosophic grounding for this type of investigation, with the qualitative interview serving as the
data collection methodology (Lopez & Willis, 2004). Although phenomenology first emerged in a
descriptive form (Husserl, 1970), it was subsequently revised by Heidegger to allow for an
interpretive approach (Lopez & Willis, 2004).

Interpretive Phenomenology

According to Heidegger (1962), the major focus of hermeneutic or interpretive phenomenology
is reflected through the existing relationship of the individual embedded in the backdrop of their
occupied world. This background is comprised of a complex interplay of bodily self, personal
being, cultural and environmental influences which, while considered both substantial and
influential, are also perceived as too complex to make fully explicit (Packer, 1985). Individual
reality blossoms through narrative reflection on meaning framed within the person/world interface.

Interpretive phenomenology engages a narrative methodology to explore the situated human
experience. The meaning of being human, an underappreciated phenomenon, becomes more
appreciated through a reflective process of unfolding (Lopez & Willis, 2004). As such, this
philosophic approach directs understanding toward human ontology, or the experience of
humanness (Annells, 1996; Solomon, 1987).

Freedom serves as an important theoretical foundation within interpretive phenomenology,
where it is considered not an absolute concept but rather as one which is situationally
contextualized (Lopez & Willis, 2004). From this perspective, humanity is actually bound by the
context of existence and conceptualized by the term situated freedom (Leonard, 1999).
Interpretation perceived from the perspective of humanity’s contextual life world serves as the
foundational element of hermeneutic phenomenology (Lopez & Willis, 2004).
Health as Expanding Consciousness and its Praxis Method

According to Newman (2002), nursing’s mission of caring in the human health experience is fostered through the emergence of unitary knowledge displayed through nurse/client engagement and subsequent unfolding of human pattern. Historically, nursing has deeply appreciated holism, yet exploration of its disciplinary impact has been limited by perception of inadequate scientific merit (Newman, 2002). Rogers’ (1970) belief in person as unitary and dynamic, existing within an undivided universe, aided the emergence of a unitary and transformative paradigm through which nursing phenomena could be explored (Newman, 1983; Newman, Sime & Corcoran-Perry, 1991; Parse, 1987), and fostered Newman’s recognition of the need to create a research method capable of capturing transformative possibilities emerging from intentional nurse/client engagement. The praxis method integrates the a priori theory of Health as Expanding Consciousness with practice and research interventions to achieve holistic understanding of meaning within the human health experience.

HEC: Hermeneutic and Dialectic

Newman’s (1994) HEC model is a hermeneutic and dialectic method of nurse/client relationship which employs discussion of meaning as a mechanism to foster revelation of unfolding life patterns within an unbroken unity of person/environmental integrity. It is thought to be particularly useful during periods of disruption and uncertainty. The nurse and client remain engaged through dialogue, allowing for achievement of insight and awareness, resulting in self understanding, growth and transformation to higher levels of human consciousness. The steps of Newman’s practice and research methods will now be described.
HEC: Practice

The nurse begins with a commitment to full personal and dialectic engagement with the client. Next, the nurse invites the client to describe meaningful persons in their lives, or meaningful life experiences. This is accomplished through the use of an initial open ended question focused on meaning, such as a query about meaningful experiences during a loved one’s critical illness. The nurse encourages the conversation to proceed as preferred by the client without offering direction or structure, but does actively participate through listening, clarification and reflection.

Narrative development evolves as the nurse places the most important statements in chronologic order, resulting in a narrative trajectory of significant events and relationships. Any breaks in fluidity, such as disorganization, a period of predictable flux or advancements are considered as revelations of evolving pattern. The nurse dwells with the data, translating the narrative into its diagrammatic representation, with patterns of client/environmental relationship noted, including relationships that are considered to be blocked, loving or uncertain.

The nurse and client reengage for a second meeting focuses on sharing and reflection. The diagrammatic portrayal of narrative data is shared, clarifications and/or revisions are encouraged, and reflections and responses to similarities and differences revealed throughout the life pattern are welcomed. Any insights noted by the client are discussed, and reflections continue until no additional insights are appreciated.

HEC: Research

Analysis of narratives and their diagrammatic representation of pattern are analyzed by the nurse researcher in accordance with Newman’s Theory of Health as Expanding Consciousness and Young’s model of consciousness expansion. Further, the pattern expression of the whole is
represented thematically. Finally, notations of shared themes are clustered for commonalities and further thematic analysis (Newman, 2008).

Current Investigation

The study purpose was to employ Health as Expanding Consciousness, and its praxis methodology, to explore meaning embedded in experiences of relationship based care among ICU family members and registered nurses within a medical intensive care unit experience. The study answered the two above noted research questions using the HEC praxis methodology employing the steps described above. The open ended question was offered to each client (family member and registered nurse participants) by the participant/researcher as an invitation to dialogue about meaningful experiences within the critical care experience. The participant/researcher transcribed the narrative and reflected on any unfolding pattern. The narrative was transformed into a chronologically organized diagrammatic representation accompanied by written comments of the emerging pattern and relationships, which was shared with client and nurse/participants individually during a second interview. The participant/researcher then thematically described each individual client/participant and nurse/participant pattern expression of the whole, and followed with an assessment of shared themes among the family member participant group, the nurse participant group and an integrated nurse/family perspective. Finally, findings were compared to extant literature among domains provided within the study’s literature review.

Sample and Setting

Study Sample

This study’s target population included families whose loved ones received care in the eighteen bed medical intensive care unit and the unit’s registered nurse caregivers. Registered nurses meeting the following inclusion criteria were invited to participate: 1) registered nurses employed
full or part time and 2) registered nurses who completed at least six months of employment. Family members eighteen years of age or older meeting the following inclusion criteria were invited to participate: 1) those whose loved one had been a patient in the unit for at least 24 hours, 2) those who visited their loved one at least once during their stay, 3) those able to verbally communicate and 4) those with English speaking capacity. Family members excluded from the study were individuals who declined, those whose loved one had a length of stay of less than 24 hours, those who did not visit their loved one, those who were unable to communicate verbally, those who were not English speaking and those who were less than 18 years of age. Registered nurses were excluded if they declined, were not full or part time employees, and did not complete six months of employment.

Recruitment

A 24 hour time frame for study participation was selected to allow family members an opportunity to begin the process of assimilation into the critical care environment. The requirement for participants to speak English was based on the necessity of dialogue within a phenomenologic study. One to two family members of a sample of five patients served as family member participants, as it was anticipated that these numbers of participants would achieve exploration of meaning. A minimum of five nurse participants were sought to explicate nursing experiences.

Setting

The setting of this study was an eighteen bed medical ICU, which cares for patients experiencing a variety of acute medical illnesses including acute respiratory distress syndrome (ARDS); sepsis; cardiac, liver, renal and gastrointestinal disorders; oncologic emergencies; and those marginalized by use of illicit substances. This closed unit is led by a Medical and Nursing
Director. Care is provided by critical care attending physicians, critical care fellows, medical house officers, a clinical nurse specialist and registered nurses, in consultation with other subspecialists.

Palliative care has been successfully integrated into this intensive care unit since 2005. Palliative integration was chosen in light of the 20% death rate in United States ICUs, elevated levels of ICU family distress and dissatisfaction, and staff conflict/distress specific to end of life decision making (Billings and Keeley, 2006). Palliative care services are directed at both ICU patients and families experiencing serious and possibly life threatening illness, with specific attention towards pain and symptom management, psychosocial and spiritual support, coordination of services and staff support, all of which are embedded within models of patient/family centeredness and shared decision making (Billings and Keeley, 2006).

Palliative integration was achieved through cultural change engendered via multidisciplinary collaboration among both clinical leadership and staff (Billings and Keeley, 2006). Specific changes resulting from this integration included the development of a Palliative Care Nurse Champion model, comprised of core, supportive ICU nursing staff who served to promote integration of palliative care principles; successful implementation of open visiting; formal and informal staff education on topics such as communication, goals of care, psychosocial assessment and management, cultural sensitivity, symptom management, suffering and ethics; withdrawal of ventilatory support at end of life; incorporation of palliative care specialists during morning rounds; promotion of regularly scheduled family meetings as a mechanism for information sharing; enhanced understanding of the patient as a person through family completion of a “Get to Know Me” poster located at each bedside; and the creation of measures designed to support staffs’ emotional needs (Billings and Keeley, 2006).
Protection of Human Subjects

IRB approval for human subject protection was obtained from both the Human Subjects Review Committee of Boston College and the participating hospital’s Institutional Review Board. Approval represented organizational agreement of adequate protection of subjects’ rights. This study was conducted by one CITI certified researcher, who was also the study author.

To eliminate any initial, direct contact among potential participants and the researcher, members of the nursing division who were not study participants were asked to approach potential study participants. Prior to this, and to prepare staff for their role, educational information was provided using unit based educational sessions, email announcements and informational fliers.

Using plain language, each participant was informed of the study purpose, its design and mechanisms through which data would be obtained, analyzed and dissipated throughout the academic community. Further, privacy and confidentiality was assured. A research fact sheet was provided prior to any information gathering activity, and participants were assured of their right to withdraw from study participation at any time and without penalty.

Potential Risks and Benefits of Study Participation

Emotional distress served as a potential risk of study participation, as exploration of meaning led to reflections which could have been emotionally painful. Families had access to emotional support provided by the hospital’s social work staff; they were informed of this resource prior to initiation of any interview activity and encouraged to seek their support should they experience study related emotional distress. Families were informed that consultation to social service staff specifically for assistance with emotional distress incurred by study participation would impact the previously established confidentiality agreement, as it would be necessary to inform the social worker of the reason for their distress; this was made explicit in the research study fact sheet.
Emotional distress also served as a potential risk for registered nurse participants, as exploration of care experiences within a patient centered and family supported ICU could reveal previously unacknowledged emotions. All staff had access to the Employee Assistance Program (EAP), a private and fully confidential staff support program. Staff were informed of this resource prior to initiation of any interview activity, and encouraged to seek support should they experience emotional distress. Staff was informed that consultation with EAP, although fully confidential, may identify them as study participants and could jeopardize their confidentiality.

This study had potential benefits as well. Newman (1994) described reflection on life patterns as a mechanism for self insight and forward movement. Through connections among participants and researcher, identification of pattern and its meaning, and expansion of consciousness through self insight and human advancement, the research process offered opportunity for expanding participants’ human growth potential through insight and human advancement.

Protection of Privacy and Confidentiality

Interviews occurred in an enclosed conference room. To prevent interruptions, signs indicating the occurrence of a interview were placed on the door. Interviews were tape recorded, with written notes taken to supplement recording, and the researcher personally maintained all tape recordings and written transcripts in a locked file cabinet. Only the researcher and the three dissertation committee members were aware of data elements during the research process. During tape transcription, actual names were removed and replaced with pseudonyms. Identifying characteristics were removed or changed during any public presentation of study information including dissertation presentation or publication.
Participant Recruitment

The unit’s registered nurses who were not study participants were asked to introduce the possibility of study participation to potential family member subjects. The Nursing Director introduced the possibility of study participation to potential registered nurse participants. Information to assist in these recruiting processes was provided by this researcher and included: 1) staff emails describing study details, 2) staff educational sessions providing in person opportunities to discuss study details and 3) an informational flier for staff to share with potential family participants.

The nurse researcher screened family members for initial entry criteria using a self created check off tool. Next, the patient’s registered nurse was queried by the nurse researcher about additional family member information, including any known capacity to verbally communicate in English. Following the initial screening process, the patient’s nurse was asked to inquire with the family member about his/her willingness to speak with the nurse researcher. If granted, the nurse researcher met with the family member to inquire about the frequency of his/her visits. The nurse researcher met with the family member to review specific study details and entertain questions only after it was determined that all entry criteria were met and the family member expressed a desire to proceed. Those who agreed to participate were provided a family member research study fact sheet and an initial interview date was scheduled.

Following family member interviews, the nurse researcher reviewed the unit assignment log for names of the registered nurses who had provided care to the family member’s loved one. Registered nurses were assessed for entry criteria. Names of those who met entry criteria were sent electronically to the Nursing Director, along with a scripted email inviting the opportunity to further discuss study participation. This email was then sent to potential registered nurse
candidates by the unit’s Nursing Director. The nurse researcher met with registered nurse candidates to review specific study details and to entertain questions. Those who agreed to participate were provided a registered nurse research study fact sheet and an initial interview date was scheduled.

Data Collection

*Uncovering Pattern in Families*

Following agreeing to participate in the study employing the recruitment methods noted above, the first interview was scheduled at a time convenient for each family member participant. At this meeting the study purpose and methods were reviewed. Also discussed was the data collection approach, taping of the interview and participant confidentiality.

The Family Sample: Data Collection

The demographic data sheet (Appendix A) and research fact sheet (Appendix B) were reviewed with each participant. Interviews occurred separately if there was more than one family member participant. Participants were informed that interviews would be taped, and that they typically lasted sixty to ninety minutes. They were also told that there would be a follow up session in the coming days to allow them to review findings for accuracy and resonance with their story. Interviews were conducted exclusively by the nurse participant/researcher.

Given the crisis of a critical illness, any specific time requests or rescheduling needs were sensitively accommodated. A second follow up session was anticipated for all participants. However, the nurse participant/researcher offered to provide written information to those who were not able to attend, with opportunity for phone follow up to validate the narrative diagram and pattern descriptions.
The family member, defined as a person having either familial or friendly relations and/or direct concern for the patient (Pochard et al, 2001) consisted of an individual who met entry criteria. The engagement process began with the nurse participant/researcher asking family members to describe significant and important life events related to their experiences with the patient, using simple, open ended questioning such as “tell me about important life events involving you and your loved one (patient)”, as suggested by Newman (2009). The interview was allowed to progress in a non-directive semi-structured manner, with the nurse participant/researcher providing prompts to expand responses or reflections for meaning and insight. The researcher was actively engaged through listening, responding and clarifying. For example, the nurse participant/researcher offered questions to assist with expanding the family member’s response, such as: “what was it like for you when you learned of your loved one’s (patient) diagnosis”. Interviews were audio taped and subsequently transcribed by the nurse participant/researcher. Discussion items that did not directly relate to participants’ life pattern were omitted at the discretion of the nurse participant/researcher.

Following the first interview, data was transcribed and the nurse participant/researcher reflected and dwelled with the data. The narrative display was created and placed in chronologic order, allowing the pattern of the whole to emerge, along with pattern and flow, as well as relationships. The nurse participant/researcher created a diagrammatic representation of the emerging pattern. The pattern was shared with family members.

During the second interview, or follow up session, the nurse participant/researcher shared the diagrammatic representation of the narrative and its emerging pattern. The family member was given an opportunity to revise or clarify the portrayal of his/her life pattern. The nurse
participant/researcher did not offer an interpretation to participants, but fostered discussion and encouraged reflection, determination of accuracy and uncovering of meaning.

Uncovering Pattern among Registered Nurses

Following agreeing to participate in the study employing the recruitment methods noted above, the first interview was scheduled at a time convenient for each registered nurse participant. At this meeting the study purpose and methods were reviewed. Also discussed was the data collection approach, taping of the interview and participant confidentiality.

The Registered Nurse Sample: Data Collection

Demographic data (Appendix C) and the staff nurse research study fact sheet (Appendix D) were reviewed with each participant. Registered nurse participants were informed that interviews would be taped and typically lasted sixty to ninety minutes. They were also told that there would be a follow up session in the coming days to allow them to review findings for accuracy and resonance with their story. Interviews were conducted exclusively by the nurse participant/researcher.

Given the unpredictable nature of the ICU environment, the nurse participant/researcher was sensitive and accommodating to any specific time requests or rescheduling needs. A second follow up session was anticipated for all participants. However, the nurse participant/researcher offered to provide written information to those who were not able to attend, with opportunity for phone follow up to validate the narrative diagram and pattern descriptions.

The nurse participant consisted of an individual who met entry criteria. The engagement process began with the nurse participant/researcher asking the nurse to describe significant and important events related to experiences with the patient and family, using simple, open ended questioning such as “tell me about important events during your care of this patient and family”, as
suggested by Newman (2009). The interview progressed in a non-directive semi-structured manner, with the nurse participant/researcher asking for extended responses to questions as necessary for meaning and insight. The researcher was actively engaged through listening, responding and clarifying. For example, the researcher may offer questions to assist in expanding the nurse’s response, such as: “what was it like for you when the family shared (topic)”. Interviews were audio taped and subsequently transcribed by the nurse participant/researcher. Discussion items that did not directly relate to participants’ life pattern were omitted at the discretion of the nurse participant/researcher.

Following the interview and its transcription, the nurse participant/researcher reflected on content items representing significant events and persons. Further, a narrative account was created and placed in chronologic order, allowing the pattern of the whole to emerge. In addition, the nurse participant/researcher created a diagrammatic representation of this emerging pattern. Finally, comments specific to practice elements within the ICU were assessed for any perceived impact on consciousness expansion among the nurse provider.

During the second interview, or follow up session, the nurse/researcher shared the diagrammatic representation of the narrative and its emerging pattern. The nurse was provided an opportunity to revise or clarify the portrayal of life pattern. The nurse participant/researcher did not offer an interpretation to participants but, instead, promoted dialogue, reflection and insight to uncover meaning.

Data Analysis

Family/registered nurse data was generated from the initial interview and its subsequent follow up, and included both the narrative summation and visual depiction of pattern. First, individual data was analyzed using the Newman method. Next, data was explored among all family
participants and registered nurse participants to examine for themes and similarities. Finally, narratives were reviewed for examples of meaning within the current experience of critical illness.

Participants’ pattern analysis was conducted by the nurse researcher as described by Newman (2009). This included: 1) analysis of the initial interview; 2) creation of a narrative based on interview data; 3) transmutation of the narrative into a diagrammatic reflection of sequential pattern configuration 4) further analysis and reconsideration of all data and 5) pictorial representation of person/environmental relationships. The researcher then 1) met with each participant to share the diagrammatic reflection of pattern; 2) invited clarification of the narrative and its diagrammatic depiction 3) engaged in dialogue regarding any emergence of pattern reflecting person-environment interaction and 4) remained in dialogue until no further insights were appreciated.

Research analysis was then performed. Narratives and their diagrammatic representations of pattern were analyzed in consideration of Newman’s Theory of Health as Expanding Consciousness and Young’s stages of consciousness expansion. Thematic expressions of pattern among individual registered nurse and family member participants were then reflected on for similarities, producing clustered themes with associated exemplars within both participant groups.

Summary

Hermeneutical formulations are encompassed within the unitary transformative paradigm. Margaret Newman’s theory of Health as Expanding Consciousness and its unitary perspective contribute to paradigmatic knowledge development via the praxis methodology. This current study has employed HEC and its associated research method to elucidate the lived experiences of family members and registered nurses providing care to critically ill patients. Thematic expressions and
their associated exemplars have emerged from the available data for both family member and registered nurse participant groups, as well as integrated among both groups.
CHAPTER FOUR

Purpose

The purpose of this study was to understand lived experiences of family members and critical care nurses using Newman’s HEC methodology to uncover pattern, meaning and insight during a patient’s critical illness. Two research questions were used to understand the experiences of family members and critical care nurses, including:

What is the family experience of relationship based care when a critically ill loved one is receiving care within a medical intensive care unit environment?

What experiences are revealed by nurses practicing within a relationship based care practice model when caring for families in a medical intensive care unit environment?

The study’s findings, detailed below, reveal the registered nurse and family patterns of health as expanding consciousness, insights uncovered during a loved one’s critical illness, unfolding awareness of the critical illness, consciousness expansion, and changes that contribute to our understanding of therapeutic and palliative care harmonization within the patient relationship and family centered care experience.

Results

Study results are presented in three sections. Study overview, participant demographics and the format for thematic analyses are provided in section one. Family member/nurse participant groups (Table 4-1) are included in section two, beginning with a brief overview of the patient’s clinical information and outcome, followed by the narrative summary. Participant responses to pattern construal and a pattern analysis summary embodied within Newman’s health as expanding consciousness and Young’s theoretical constructs are also provided. Section three includes thematic analyses insightfully established from the participant researcher’s data examination.
Themes are analyzed from the outlook of family members, critical care registered nurses and, finally, from an integrated family member/registered nurse outlook.

Section One

Overview and Thematic Analysis Format

The client/participant and participant/researcher convened in dialogue employing the HEC praxis method outlined by Newman (2008). Family members were asked to discuss meaningful experiences with their loved one, who was now critically ill, while registered nurses were asked about meaningful experiences of care provision for the critically ill patient and family. The tape recorded storytelling proceeded at the client/participant’s pace, with the participant/researcher focused on achieving an enhanced understanding of meaning by employing active listening and authentic engagement. The participant/researcher then created the narrative by transcribing the taped dialogue, assuring anonymity by recoding actual names to contrived names. Additionally, the narrative was transmuted diagrammatically to represent sequential information including the configuration of relationships and meaningful events. A follow up meeting was convened to review the diagram, inquire about its accurate portrayal, and elicit any additional information the participant wished to share. Any enhanced awareness or transformational changes shared by the participant was noted. Individual family member and registered nurse patterns were created. Finally, family member and registered nurse patterns were analyzed in aggregate to assess for the presence of thematic similarities.

Sample

A total of 15 study participants were recruited, including eight family members and seven registered nurses. All family members completed the first interview. One family member was lost to follow up following the initial interview. Consequently, a registered nurse participant was not
recruited for this participant group. One registered nurse who agreed to be interviewed was ultimately unable to participate.

**Family Member Characteristics**

**Subjects**

Eight participants comprised the family member sample, with seven participants reporting a numeric age, and one participant who preferred to offer “greater than 21 years”. Participant ages ranged from 29 to 83 years (M=58.5 years; SD=18.7). All participants were female except for one. Seven of the eight family members endorsed their race as white; one participant categorized their race as black, offering further racial elaboration as American West Indian decent. Religious denomination varied within the group, including four Catholic participants (50%), two of Protestant faith (25%) and two who noted their faith to be “other” (25%); one individual further elaborated on their faith as Greek Orthodox. The majority of participants were either married (4; 50%) or divorced (3; 37.5%); one participant (12.5%) was never married. Family member connections included spousal relationships (n=4; 50%), an adult child (n=1; 12.5%), a meaningful person (n=1; 12.5%) and two (25%) who categorized themselves as “other”, including a fiancée and a mother. All visited their loved one more than 5 times. Participant educational levels ranged from college graduate (3; 37.5%), those who had some college education (3; 37.5%) and those who completed a high school education (2; 25%). Two of the three college graduates noted additional post graduate education. Four participants were employed full time (50%), two worked part time (25%), one was unemployed (12.5%) and one was retired (12.5%). Five of the eight participants (62.5%) had salaries that ranged from $25-50,000, one (12.5%) reported a salary greater than $50,000, one (12.5%) reported a salary < $25,000 and one participant (12.5%) chose
not to report salary level. Patients’ ICU length of stay ranged from 6 to 25 days (M= 12.3 days; SD= 6.18).

Registered Nurse Characteristics

Subjects
Six individuals comprised the registered nurse sample. All of the participants were female. Three (50%) reported ages within the 30-39 range, two (33.3%) described their age as ranging from 20-29, and one (16.7%) placed herself in the 40-49 range. Overall nursing experience varied among four categories, including 16-20 years (n=1; 16.7%), 11-15 years (n=2; 33.3%), 6-10 years (n=2; 33.3)) and 0-5 years (n=1; 16.7%). Registered nurse participants reported the duration of their MICU experience within either the 11-15 year range (n=3; 50%) or the 0-5 year range (n=3; 50%). Four participants (66.7%) were educated at the BSN level, one participant (16.7%) had an AD degree and one participant (16.7%) obtained an MSN.

Section Two
The following section contains information from participant groups one and two, including participants’ narrative summaries, their responses to the pattern analysis, and the pattern analysis summaries. These groups were selected as they reveal information suggestive of emerging understanding among both family member and registered nurse participants. Data for the remaining participant groups is housed in Appendix E.
### Table 4-1

**Participant Groups**

<table>
<thead>
<tr>
<th>Group Number</th>
<th>Patient Information</th>
<th>Family Participant</th>
<th>Nurse Participant</th>
</tr>
</thead>
</table>
| One          | An older male with ARDS who died in the ICU following readmission | Wife: Anna  
Daughter: Ava | Nurse: Barbara  
Nurse: Brenna |
| Two          | A middle aged male with septic shock who died in the ICU | Fiancée: Charlene | Nurse: Diane |
| Three        | An older male with end stage liver disease who died in the ICU following readmission | Wife: Evelyn | Nurse: Grace |
| Four         | An older male with septic shock who survived to ICU transfer | Wife: Helena | Nurse: Irene |
| Five         | An older male with septic shock who survived to ICU transfer | Partner: Linda (Lost to Follow Up) | Nurse: None |
| Six          | An older female with multiple medical problems who died in the ICU | Husband: Max | Nurse: None |
| Seven        | A young adult female with recurrent PNA pneumonia who survived to ICU transfer | Mother: Rose | Nurse: Stephanie |
Participant Group One

Patient information: Mr. A was a man admitted to the MICU following an episode of clinical instability on the general care unit, including respiratory distress requiring intubation. The patient died of Adult Respiratory Distress Syndrome (ARDS) on day ten of his MICU readmission, following the family’s decision to transition to comfort measures only.

Participants: patient’s wife Anna, daughter Ava, MICU RN Barbara and MICU RN Brenna

Anna’s Narrative Summary and Narrative Diagram

Anna’s family life had been distinguished, until this episode of critical illness, by the stroke her husband sustained in 1990. She noted “…everything is dated by that; before you (Mr. A) lost your job and after you lost your job.” Anna and Mr. A began dating at the age of 16. Their relationship continued through college and Mr. A’s law school graduation, progressing to marriage and the birth of their first child, a son. The family unit was placed into a state of disorganization following the birth of their second child Ava, as Anna became critically ill during Ava’s delivery, with both mom and daughter requiring an extended hospitalization. Anna described this experience as one that revealed Mr. A’s loving devotion to both her and the children. He visited them daily, assisted with Ava’s feedings, and cared for their son. Anna stated “…the nursery nurses told me…they had never seen anybody like him”, which helped her realize how lucky she was to be married to Mr. A. Anna described her post partum illness as “…the first real biggy” which, while frightening, represented a crisis from which the couple was able to successfully emerge. Mr. A. continued to provide exemplary family support, and his financial success allowed the couple to purchase their first “dream” home.

Mr. A’s stroke, while described by Anna as mild, impacted the family significantly. Mr. A was forced to resign his law firm position. Dreams for continued personal and professional
advancement were shattered. Role reversal occurred as Mr. A became a stay at home dad, and Anna entered the work force. Expectations were adjusted, as the “dream” house was sold and a smaller home was purchased. Anna described the financial adjustments as having a stronger impact on Mr. A than her, as he has been raised more financially advantaged. Anna spoke about the bitterness she felt towards the stroke and its impact on her smart, deserving husband’s lost future. That he has never gotten “back on his feet” remained “under the surface” of their relationship.

The risk of death posed by Mr. A’s current critical illness provided a new perspective for Anna. She reflected on their capacity to remain connected as a couple throughout past major events, and that her fear of losing Mr. A illuminated “what is important and what is not”. Anna reflected on how their friendship has always been the most salient element of their loving companionship and that this, more than the bills and other stressors, has now become her most prominent thought.

Anna described her own health issues, and the belief among her family members that she, rather than Mr. A., would be the first to experience serious illness. She also described her personality type as more vivacious, compared to Mr. A’s gentle and reserved nature, and reflected on these differences as likely the result of their varied backgrounds and ways of being, as Mr. A is Irish Catholic and reserved, while Anna is Greek and forthcoming without hesitation. Anna believed these marked differences helped them to learn and grow together as a couple. Anna described Mr. A’s illness as one that has broken their bond, noting: “half of me is missing”. Though his voice has been silenced by the endotracheal tube and its requisite sedation, she longs to hear him say that he is going to be “alright”.
<table>
<thead>
<tr>
<th>Marriage</th>
<th>Son's Birth</th>
<th>Daughter's Birth</th>
<th>Life As A Young Family</th>
<th>Life As A Developing Family</th>
<th>Husband's Critical Illness</th>
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</table>

**Participant Group One**

Anna (Wife)

- **Dating future husband since age 16**
- **Uneventful delivery**
- **Prolonged hospitalization for both Anna and her daughter; the first “biggy”**
  - Anna calmed by and appreciative of husband’s caring devotion; cared for son, and helped with daughter’s feedings
  - Purchased dream home
  - Husband’s successful law career led to family’s financial security

- **Husband’s stroke; the second “biggy”**
  - Husband lost job
  - Financial concerns
  - Anna became breadwinner
  - Life events dated by husband’s loss of job
  - The third “biggy”

  **Realizations:**
  - Their life events have strengthened their marriage; would have made other marriages fail
  - Daughter’s prolonged hospitalization created opportunity for mother/daughter bonding
  - Appreciated the impact of being at bedside and being invited to ask questions on her capacity to achieve insight

<table>
<thead>
<tr>
<th>Anna</th>
<th>Anna</th>
<th>Anna ↔ Daughter</th>
<th>Husband → Family</th>
<th>Husband ↔ Anna</th>
<th>Husband ↔ Anna</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husband</td>
<td>Son</td>
<td>1 Son/Daughter</td>
<td>Family</td>
<td>Family</td>
<td>ICU Daughter</td>
</tr>
</tbody>
</table>
Anna’s Response to the Pattern Analysis

The transmuted diagram of Anna’s narrative beginning with her marriage to Mr. A. and culminating in his current critical illness was shared with Anna during the second interview, providing Anna the opportunity for reflection and clarification. Anna offered details on the realizations she achieved during this second dialogue.

A) Other couples may have divorced in the face of similar life crises but, for Anna and Mr. A., life experiences including the prolonged hospitalization following Ava’s birth, Mr. A’s stroke, and the illnesses of both her mother and mother-in-law all served to strengthen their marital bond.

My mother was very, very sick with cancer. And when she got sick, we did hospice, and she came to live with us. And, ah, Ed was like a rock of Gibraltar. When his mother got sick she came to live with us. And everybody said, ha, you must be out of your mind with your mother-in-law. I wasn’t. Even though she was so different from me…to the point where my mother-in-law did not believe that women should wear denim or dungarees or jeans. So in the back of the bathroom door there was a hook with a pair of regular pants. And we had built on a mother-in-law apartment. She was in her 90s, so she was not zipping around or anything like that. But she would call “Anna” and I would say “coming” and before I went in I would whip into the bathroom, take the jeans off and people would say oh, you are such a hypocrite and I would say, no, it makes her happy. And it doesn’t bother me to do it. You know, she doesn’t believe that women should wear them; she thinks they are too revealing and she is from another generation and, you know, we did it but those are the little things we did for each other.

B) The extended post partal hospitalization strengthened the bond between her and her daughter.

C) Nursing’s provision of unrestricted bedside presence coupled with their openness to her questions allowed her to achieve meaning and perspective on the primary importance of her relationship with Mr. A over all other elements within their lives. Anna questioned her ability to achieve this outcome in a more restrictive and less family centered ICU.

And when I go home I am not anxious ‘cause I can call and when I do, people talk to me. That makes a big difference. I called the other night at 3 o’clock in the morning and I was crying, and they just stayed on the phone as long as I needed them to. And it
wasn’t a long time. But they were not rushed or putting me on hold or I have to go take care of this. I was their focus of attention. And it got me through the night. I was able to get off that phone and, and take a breath. Maybe I didn’t sleep but it wasn’t cause I was anxious any more; it was OK. She told me what I needed to hear or he told me what I needed to hear.

I feel like, I don’t feel anybody is hiding anything from me. Like I say that is why I can go home and relax and know OK. It has been a good experience even though it has been a bad one. My daughter and I were talking about this on the way in. We are going to come out of it even better than when we went in it because we have all been able to reevaluate daddy and daddy in our lives. Because maybe we have all taken him for granted, and this is a little wake up call for all of us and even for dad because dad has never been sick.

Anna’s Pattern Analysis Summary

Anna’s pattern revealed a life of major events, described by her as “biggies”, all of which fostered greater relational meaning within her marriage. The birth of Anna’s daughter and the subsequent prolonged hospitalization she and her baby experienced enhanced her understanding of her husband’s caring and compassionate nature. Despite the crisis, she reflected on the period positively, clearly articulating the event’s illumination of her husband’s devotion towards her and their family. The event strengthened the bond between her, her daughter and her husband.

Mr. A’s stroke represented the couple’s next major crisis. Despite feelings of bitterness towards its impact on Mr. A’s career, Anna grew to appreciate the stroke’s impact on their ongoing development as a couple. Anna noted Mr. A’s tremendous support as she cared for both her mother and mother-in-law at the end of their lives. She shared Mr. A’s transition from attorney to playwright, and the couple’s pride when one of his plays was produced at the Kennedy Center in Washington, D. C. Anna also noted, retrospectively, that the role of attorney may have not have been the best fit for Mr. A’s personality, as his compassionate nature often invited clients’ connections with him at home, challenging work/life boundaries. Indeed, Anna was able to view
the stroke as a mechanism by which alternate goals offering greater harmony with Mr. A’s personality type could be accomplished.

In addition to recognition of the marital strength fostered through the couple’s prior life crisis events, Anna’s pattern analysis revealed the family centered care environment’s impact on refocusing her towards the meaning of her husband’s valued friendship. Anna acknowledged nursing’s provision of unrestricted bedside presence and welcoming approach to questions as avenues by which she achieved this perspective. Mr. A’s illness coupled with the provision of caring nurse strategies enhanced Anna’s awareness of their valued friendship, assisting her transition from stage three to stage four of Young’s spectrum of evolution. The real possibility of death and her fear of losing Mr. A., coupled with the provision of family centered nursing care, advanced Anna to a new understanding of “what is important and what is not”, guiding her to an renewed appreciation of their friendship as elemental within their relationship. The pattern expression of the whole is represented by the theme “Sustaining Strength and Achieving Understanding in the Face of Life Crisis Events by Engaging in Supportive Relationships with Family Members and Nursing Staff”.

Ava’s Narrative Summary and Narrative Diagram

Ava, the second of the couple’s two children, recalled her early childhood relationship with her father as one distanced by his long work hours as an attorney. Their life together changed dramatically following Mr. A’s stroke and new diagnosis of narcolepsy, both of which forced him to become a “stay at home dad”. Ava recalled this life style change fondly, describing it as one which allowed them to spend daily time together. A close father/daughter bond was fostered, with her dad’s attention making her feel like a “princess”. This new found relationship with her father
supplemented the existing closeness she experienced with her mom; she now felt loved by and connected to both parents.

Mr. A’s stroke provided Ava with an appreciation for life, and accentuated the importance of not taking life with her dad for granted. Ava was comforted by her assurance that Mr. A understood how much she loved him, and felt compassion towards others who did not have this type of assurance. In addition to her own dad’s health issues during her childhood, Ava also witnessed the collapse and death of her best friend’s father. She described this event as traumatic, but one that further reinforced how blessed she felt for her dad’s life and their relationship together. Despite her keen awareness of life’s fragilities, she deeply hoped for her dad’s recovery and his future participation in traditional father/daughter activities during anticipated life celebrations.

As Mr. A’s respiratory symptoms worsened, the care team requested a patient, family, team meeting to discuss intubation. Ava was terrified by this conversation, but appreciated both the opportunity to observe her dad participate in an informed decision making process and to witness his readiness for intubation. Mr. A. had become extremely fatigued by his work of breathing, and acknowledged this by saying “I am looking forward to it” (intubation).

Mr. A’s ICU experience has been a rollercoaster ride for Ava. She has cried “for days”, attempting to regain control by processing the information provided by clinical staff. She has recognized the need to have “more faith” in her dad’s ability to foster his own recovery, as she is sure he does not want to die, and that he will do his best to allow the treatments and medications to be successful. While she described herself as someone who almost never worries preemptively, she now finds herself consumed by anticipatory concerns.
Ava described the care team as incredibly patient, responding to all of her (and her mom’s) questions. She worries about “abusing” the team’s willingness to answer questions, but is desperate to hear answers that include “key words” such as “better” or “moving in the right direction”, irrespective of the amount of time required to achieve recovery. She is also extremely comforted by communicating with him and seeing him respond through raised eyebrows or head nodding. The ability to connect with her dad this way has been extremely positive for Ava, making her feel “like a million dollars”. While her dad’s illness was completely unanticipated, she is calmed by hearing clinicians describe events as “anticipated”, as she interprets this as normalizing the event and its intervention(s). Ava described her experience with the unit’s open environment …if I wasn’t able to experience this with him I would be a completely different person right now…I would probably be nuts, but them letting us be there, and I don’t know if we have been in their way but I don’t think it has affected his progress of anything either, has made this completely bearable situation in what would have been an unbearable situation for anybody.
Ava - Dad's Childhood
- Dad's Stroke
- Witnessed Death of Friend's Dad
- Dad's Critical Illness

Death of Ava's friend's dad

Ava - Dad

Hearing voice offers energy

Feeling blessed to be with him and see him

Tending to dad and health care team

Trying so very much to hear the words "better"

Ava

Fearful, Teary

Refusal to attend sports event with him because she didn't know him well enough

Dad's new role - stay at home dad, long work hours

Dad took on role of stay at home dad

Felt strong appreciation for dad

Renewed importance of dad

Long relationship with dad due to his long work hours

1. Ava (Daughter)
Ava’s Response to the Pattern Analysis

Ava did not participate in a second interview with the participant researcher. Although the opportunity was offered, she was too distracted by her dad’s clinical decline. This decision was respected by the participant/researcher.

Ava’s Pattern Analysis Summary

Mr. A’s stroke fostered Ava’s personal growth as she found meaning and value within her father/daughter relationship. She appreciated the newfound closeness between her and her father, which was distinctly different from their prior life together. In the past, she had refused to attend a ballgame with her dad, because she felt she didn’t know him well enough. Now, they were enjoying their daily time together. She learned that time with him was not to be taken for granted, a lesson that was accentuated by witnessing the sudden death of her friend’s father.

The crisis spawned in Ava’s life by her dad’s need for intubation was partly attenuated by her participation in the family meeting to discuss intubation, and her observation of Mr. A’s response. Ava did not participate in the pattern analysis, so it is not possible to know if this crisis led to personal growth and a new level of organization. However, she did report feeling comforted by the care team’s information and by her dad’s beginning ability to respond nonverbally. She also noted her ability to have faith and trust in his capacity to mobilize a positive response to the medications and treatments provided. These may represent Ava’s appreciation of her self limitations and potential for inner growth, both of which are elements of the fourth stage of Young’s model. The pattern expression of the whole is represented by the theme “Despair Tempered by the Promotion of Father/Daughter Engagement through the Critical Illness Experiences Employing Informed Decision Making, Open Access and Normalization”.
Barbara’s Narrative Summary and Narrative Diagram

Barbara cared for Mr. A. only once during his first MICU admission. She was able to interact with him directly, as he was extubated, lucid and conversant. Barbara’s nursing care expanded beyond the provision of direct care for Mr. A. to include encouraging his daughter Ava’s bedside presence, responding to her questions, and providing telephone updates to other family members.

Barbara described Mr. A. as a “very, very, nice man”. She recalled his complaints of thirst, and felt bad that she was only able to offer single sips of water because of his tenuous respiratory status and risk for aspiration. Barbara described him as very accommodating to the limitations she placed on his oral intake. One of Barbara’s goals was to help Mr. A. regain his physical strength by ambulating him from bed to chair, and she remembered how he was genuinely concerned that this activity would increase her workload. Barbara reassured him of the benefit provided by ambulation, and assured Mr. A that her role was to provide interventions that would help foster his recovery.

Barbara also had fond recollections of Mr. A’s daughter, describing her as “as nice as he was”. Ava spent three or four hours with her dad during Barbara’s shift. Ava was apologetic about the number of questions she was asking, yet Barbara was impressed with the quality of Ava’s questions, describing them as “very good questions”. Barbara assured Ava that her questions were welcomed, and that responding to family questions was a component of MICU nursing practice. Barbara also acknowledged and was impressed by the kindness Ava demonstrated towards her father. Barbara provided an update to Mr. A’s son by phone, as he requested a review of the update he received from his sister.
Barbara (RN)

<table>
<thead>
<tr>
<th>Barbara’s experience with patient</th>
<th>Barbara’s experience with patient’s daughter</th>
<th>Barbara’s experience with patient’s son</th>
<th>Barbara’s feelings</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Very, very nice man</th>
<th>Daughter was as nice as patient, and kind to her dad</th>
<th>Barbara spoke with son via phone</th>
<th>Barbara hoped he would do well</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient graciously accommodated PO intake limitation d/t aspiration risk</td>
<td>Barbara spoke with daughter during her 3-4 hour visit, answering questions, etc</td>
<td>Son acknowledged receiving a prior update from his sister, but requested an update directly from Barbara</td>
<td>Barbara felt sad to learn of his ICU readmission and that he was doing poorly</td>
</tr>
<tr>
<td>Patient concerned about burdening Barbara when she encouraged ambulation; she reassured him of the benefit of mobility, and also assured him that it was her job to assist him in this activity</td>
<td>Barbara acknowledged daughter’s excellent questions</td>
<td>Barbara gladly provided an update to the patient’s son</td>
<td></td>
</tr>
</tbody>
</table>

Barbara ← Patient → Barbara ← Patient → Son → Husband

Daughter ← Barbara → Daughter
Barbara’s Response to the Pattern Analysis

Barbara acknowledged the accuracy of the transmuted diagram’s reflection the nursing care she provided during the eight hours spent with Mr. A and his family. She recognized it as composing a predictable flux within the provision of MICU nursing care which acknowledges the patient/family dyad as the unit of care. Barbara did not offer any further insights.

Barbara’s Pattern Analysis Summary

Despite caring for Mr. A and his family for only one eight hour shift, Barbara’s narrative offered a glimpse into the interconnectedness between Mr. A., Ava and Barbara. Providing information and facilitating family member presence continued to help Ava manage her sense of crisis, as she previously reported the value of information sharing on helping her regain situational control. Barbara also attended to Mr. A’s care needs including prevention of aspiration and strength enhancement through mobilization. Barbara’s individually focused patient and family centered practice represents consciousness development within stage 3 of Young’s evolutionary model. The theme of “Limiting the Crisis through Caring and Information Sharing” emerged as the pattern of the whole.

Brenna’s Narrative Summary and Narrative Diagram

Brenna recalled her memories of Mr. A’s first MICU admission. Although she never provided direct care during his first MICU stay, she remembered his post extubation period as one during which he struggled with hypoxemia. Despite his ongoing clinical issues, she recounted her colleagues’ descriptions of him as a wonderfully kind individual. She also recalled specifics of his first preintubation period, describing him as nervous about the possibility of intubation but extremely calm in knowing that he wanted his wife to be present.
The majority of Mr. A’s night shift care was provided by Brenna during his second MICU admission. He required heavy sedation and pharmacologic paralysis to achieve ventilator synchrony with ARDSNet ventilation so, despite caring for him, she never interacted with him directly. Instead, her interactions were focused towards Mr. A’s family.

The unit’s philosophy of family presence afforded Mr. A’s family direct access to the bedside for unlimited periods of time and also offered them opportunities to observe the multiple clinical interventions being provided. Together, these experiences helped the family develop an informed understanding of Mr. A’s clinical status. Brenna described her role in achieving this outcome as one focused on encouraging family presence and educating the family about specific elements of care. Their responses to these interventions led her to appreciate the important role information played in enhancing their coping skills. She offered the example of Mr. A’s family member calmly seeking her assistance, saying “I think he’s fighting the vent a little bit”, as realization that they absorbed her teaching about the importance of patient synchrony with ARDSNet ventilation.

Brenna described her assessment of a family’s capacity to absorb information in terms of their cognitive abilities coupled with the impact their coping has on these abilities, using these elements together to “…sort of figure it out as you go along”. Her initial approach to initiating a trusting nurse/family relationship is to encourage family bedside presence, which often enhances family comfort and creates opportunities for dialogue. Then, she offers small amounts of information, assessing the family’s ability to assimilate information and build upon it. Brenna observes and assesses family members’ anxiety level, often finding that information helps to reduce anxiety…”they are more at ease”. Brenna also employs normalization as an approach to quell family member anxiety. She stated:

I think they sit in the room and they look at all the pumps, and watch the vent, and it makes a funny noise and the alarms go off and they get nervous, but I think if you just
say oh, that is just alarming because of this reason, we expect it to happen, don’t worry about it, I think you can tell, you know.

Brenna loved caring for Mr. A. and his family, partly because she admired how wonderful they were to each other. She also achieved a profound understanding of their needs, and provided knowledge based interventions accordingly. For example, Brenna knew Mr. A’s daughter slept very soundly in the bedside cardiac chair, but had sleepless, worry filled nights at home. She used this understanding to successfully counter a physician recommendation that Ava return home to sleep.

Brenna described her belief that ongoing family presence coupled with free flowing information eased Mr. A’s family’s end of life decision making. It offered them transparency to all that occurred, helped them grasp the likelihood of futility and facilitated the decision making process. She stated:

I think in the long run they, they made the decision, I think that they came to the point of withdrawing sooner than anybody else did. I think that they very much, for a couple of days his sats were in the low 80s and they knew we had done everything and, I think that although they were like…tell us there is more to be done…they knew there wasn’t you know, and I don’t think they questioned…they didn’t question anything else once you told them that because they had been involved since the beginning.

Brenna also expressed concern about family outcomes among those receiving care in more restrictive intensive care units:

…I imagine in another ICU where you are only allowed brief periods of time… I wonder how those conversations are…I bet they are more difficult…And even if the conversations are presented the same, I suspect that afterwards the… I suspect that the family has a lot more…I bet they second guess it and I think it is probably more stressful after the person dies wondering like…did I make the right decision…could we have done more…did they try this, that. I am sure they talk to people (outside of the hospital) who say…did they do this, did they try this, and I think they probably don’t know.
**Brenna’s Response to the Pattern Analysis**

The transmuted diagram of Brenna’s narrative beginning with her initial awareness of Mr. A. during his first MICU admission and culminating with her ongoing care during his second admission was shared with Brenna during the second interview, providing Brenna the opportunity for reflection and clarification. Brenna acknowledged and was amazed by the accuracy of the transmuted diagram’s representation of her narrative description of her care patterns during the multiple days spent with Mr. A and his family. While initially concerned that there was more information she should have shared during the interview, her review of the diagram reinforced her belief that the most salient elements had been discussed. Brenna did not have any further insights.

**Brenna’s Pattern Analysis Summary**

Brenna’s descriptions of care reveal the specific strategies she employs to foster health and consciousness expansion among family members. Brenna begins with family presencing to achieve trust, and then assesses the family’s cognitive capacities and their coping skills. She offers small amounts of information, assessing their subsequent capacity to integrate the information into their analysis of the care issues. She also continually assesses anxiety levels, offering normalization as an intervention to help reduce family anxiety. Brenna’s devotion to individualizing family centered critical care represents a choice point in her nursing practice focused on addressing unique family needs, embedding her work in the fourth stage of Young’s model of consciousness evolution. The pattern expression of the whole is represented by the theme “Developing and Sustaining Family Consciousness Expansion through Presence and Information Sharing”.
Participant Group Two

Patient Information: Mr. C was a man admitted from an outside facility with a diagnosis of shock due to sepsis. While he was rescued from his shock state, he experienced residual damage due to severe shock-related hypotension, including tissue necrosis of his nose, hands, and feet. The long term treatment plan would involve bilateral hand/foot amputations, an intervention with significant life altering consequences. This initial plan was considered acceptable by his fiancée, who was also his health care proxy, as she was hopeful that prosthetics could provide an acceptable level of functional recovery. However, Mr. C then developed additional complications which severely impacted his chances of achieving any meaningful functional recovery.

Mr. C improved clinically, but his capacity to engage in decision making was compromised. Conflict erupted following a family meeting, as it was the family’s understanding that the meeting’s outcome was to allow the patient and family time for goodbyes prior to a conversion to comfort measures only and subsequent death, while the medical team understood the decision to involve waking Mr. C to allow him to participate in the decision making process. Nursing emerged as the discipline with which the family felt trust and comfort. The nurse participant in this interview was the key negotiator in establishing a collaborative plan for the patient’s death.

Participants include Mr. C’s fiancée Charlene, and MICU RN Diane.

Charlene’s Narrative Summary and Narrative Diagram

Charlene described Mr. C as being passionate about his boat, which provided both personal stress relief following a long work day, and served as a place for family gatherings such as fishing trips, etc. Charlene used story telling, including stories about the boat, to help Mr. C emerge from the most intense period of his critical illness. Returning to his fishing boat was the hoped for future, and Charlene reassured him that the boat would be waiting for him whenever he was ready.
She was also landscaping his rehabilitation by researching the availability of prosthetics designed to help pull fishing traps.

Mr. C’s late father served a meaningful role in his life. Mr. C hoped to maintain a tangible connection with his dad by installing his father’s business signs in their family den, but he ran into a road block when his mom argued against his request. Charlene knew that Mr. C’s love for his mom prevented him from expressing his true feelings. She also knew that the argument was simply their way of communicating. Charlene both countered his mom’s guilt and helped her be more reality based by reminding her that these material things have now become “small stuff”. Charlene “can’t wait” to hear Mr. C and his mom argue, as it would symbolize movement toward his recovery.

Charlene knows that Mr. C becomes emotionally upset when he is frightened and, when this happens, she often serves as his rescuer and interpreter. For example, she planned to explain to his mom why he wanted the business signs, but the conversation was interrupted by this illness. Charlene described Mr. C’s angry outburst towards her two children when he realized they had returned home from school to discover the house had been broken into, but didn’t seek help. Charlene knew that fear for the children’s wellbeing was driving his misplaced emotions. She helped him regain control, apologize to the children, and reflect more honestly on how fear influenced his behavior.

Charlene also talked about Mr. C’s kindness towards her former husband and the father of her two children, a homeless alcoholic. Mr. C. provided him shelter during inclement weather, but also didn’t hesitate to use a “tough love” approach when he embarrassed the children by visiting them at their after school library program. They have partnered in their concern by checking him into a rehabilitation facility, and are pleased that he recently transferred to transitional services. They
visit weekly to both bring needed supplies and allow the children visit time. Charlene commented that Mr. C’s love for her was partly based on her concern for her former husband’s safety.

Mr. C has proposed marriage multiple times, but the financial expenses incurred from her divorce consistently prevented Charlene from accepting. She told him “…it doesn’t cost us anything, not to be married”, but he has countered with “…we need to be married; if something ever happens to me, you need to have my social security; I need to know that you are taken care of”. Charlene continued “…and now I’m like, he’s right”.

Charlene described how she declined his first proposal, and the specifics of his second marriage offer. She returned home from work on Valentine’s Day to find Mr. C and her two children on their knees. While wanting to decline, she was influenced both by her daughter’s comments “…I want to say he’s my stepfather, I don’t want to way he’s my mother’s boyfriend” and Mr. C’s willingness to shoulder the financial cost of divorce, should it ever occur. Charlene regrets her decision to stall the second proposal because, despite being his proxy, she is unable to access financial supports such as his Social Security disability benefits.

Charlene feels somewhat prepared to serve in the proxy role because, as a result of Mr. C’s involvement in decision making following his dad’s heart attack, Mr. C has articulated his own advanced planning goals to include avoidance of any sustained dependence on life support. Yet, that they had never envisioned this type of rapid onset illness left her feeling alone and unsure about the decision making process. She noted: “we never talked about an infection just riddling through you, or do we amputate your hands; we didn’t talk about this”.

At the outset of Mr. C’s illness, Charlene asked her aunt, who is a registered nurse, to render an opinion about Mr. C’s chances of survival. During the first few days of his illness, her aunt reiterated assurances that Mr. C would not survive. She told Charlene to “…figure out what you
are going to do, start planning on good bye”. This conviction transpired into a level of uncertainty as Mr. C began to demonstrate clinical progress, and then further advanced to amazement as he began to exhibit signs of significant clinical improvement. Accordingly, Charlene is planning the long road, one of uncertainty, but one that she knows she will be able to figure out.

Charlene is also working to normalize life for her two children, aged 15 and 13, allowing them to visit on weekends, but returning to school during the week. The oldest, her daughter, was described by Charlene as academically strong but with “anal retentive panic” tendencies while her son, the youngest, is the “resister”. Her son hoped to remain at the bedside to protect Charlene, and expressed this by saying “who is going to protect you if he dies?” Her son also talked to Mr. C about various future plans and, when Charlene commented on how much he was talking, responded by saying: “if he hears me, he knows I still need him.”
<table>
<thead>
<tr>
<th>Marriage</th>
<th>Divorce</th>
<th>Creating New Relationship</th>
<th>Way Finding in New Relationship</th>
<th>Fiancée's Critical Illness</th>
</tr>
</thead>
</table>

- **Husband's alcoholism negatively impacted Diane and children**
- **Divorce expense ($27,000)** negatively influenced future capacity to commit to relationships
- **Online dating**
  - Met patient
  - Introduced patient to her children
- **Appreciating each other's gifts**
  - Patient's calm, lack of drama and caretaking skills
  - Charlene's capacity to help patient express feelings
  - Patient's goals of care influenced by his dad's illness
- **Sudden Illness**
  - Unexpected initial survival
  - Necrotic limbs
  - Charlene/family accepting and living patient in setting of the illness's impact on his life
  - Long term recovery and probable need for prosthetics, etc.

- **Charlene, Husband, Children**
- **Charlene**
  - Ex-husband
  - Children
- **Charlene**
  - Patient
  - Children
- **Charlene**
  - Patient
  - Children
Charlene’s Response to the Pattern Analysis

The transmuted diagram of Charlene’s narrative, beginning with her prior marriage and culminating with this current critical illness, was shared with Charlene during the second interview, providing her the opportunity for reflection and clarification. Charlene validated the timeline, and indicated that the events were accurately portrayed, but was unable to be reflective. Instead, her goal was to spend as much time with Mr. C as possible, and left soon after our discussion began to join him at his bedside.

Charlene’s Pattern Analysis Summary

Narrative analysis reveals numerous examples of chaos in the lives of Charlene and Mr. C which, when considered as individual events, appear random but, when considered in totality, represent underlying crises from which their individual coping skills did not more fully develop. Mr. C’s inability to verbally express his loving intentions resulted in use of behavioral approaches which inaccurately portrayed his true feelings. Examples include the family angst surrounding his late father’s business signs, and the home break in which the children failed to report. These chaotic moments are subsequently calmed or repaired through Charlene’s translational efforts. Yet, Charlene experienced similar limitations, as she was unable to move beyond the emotional distress of her prior marriage and subsequent divorce to accept Mr. C’s marriage proposal. She, too, was enmeshed by the impact of prior life events on her individual characteristics. Finally, as this crisis unfolded to the point of necessary decision making, and the untenable options from which choices needed to be made, the entire family required the assistance of the nurse, acting as the compassionate stranger, to serve in Charlene’s former role as translator.

Accordingly, Charlene is in the third or centering stage of Young’s consciousness development theory. Her identity as an individual is well established and, in fact, continues to be represented
through the series of life crises. There has been no movement to the forth stage, or choice point, where insight emerges and results in alternate decision making reflecting the advancement of human consciousness. The pattern expression of the whole is represented by the theme “Inability to Fulfill Goals of Care Interpretation in the Face of Lost Hope, Uncertainty and Death”.

Diane’s Narrative Summary and Narrative Diagram

Diane’s initial care for Mr. C was provided during the first three days of his MICU hospitalization. She described day one as enormously challenging due to his extreme clinical instability from shock due to sepsis. Her goal for day one was to establish renal replacement therapy (CVV) in the midst of attempting to achieve hemodynamic improvements via fluid resuscitation, vasopressors and antibiotics. Her goal was achieved, but only for the short term, as the CVV system crashed soon after initiation. She felt unaccomplished by the end of day one, but was reminded by colleagues that her accomplishments were evidenced in the fact her very sick patient was still alive. She successfully resumed CVV and, along with other high intensity interventions, provided Mr. C with very tenuous clinical stability. By the end of day three Diane knew that Mr. C’s overall outcome was unclear, but was sure his necrotic extremities would require amputation.

Diane did not participate as a caregiver for Mr. C during the next two weeks, but did follow his clinical course, and was pleased to learn of his ongoing improvements, including ventilator liberation. She also learned that he was not discussing his necrotic extremities, which she perceived as a reflection of his inability to process such a devastating outcome. She appreciated the family’s ongoing crisis as they engaged in the amputation decision making process, knowing he wouldn’t want a life without extremities “…because he was a truck driver and lobster fisherman, and these things were important to him”.
Diane resumed caring for Mr. C during the last three days of his MICU hospitalization, an experience she described as even more difficult and exhausting than that which she experienced during his first three days. The work of her second tenure with Mr. C was not aimed at applying highly technical life saving interventions as she did during the first three days but, instead, was aimed at repairing discord between Mr. C’s family and the medical team, both of which had different goals and impressions. Diane described the family’s experience as a “horrible two week period” of frustration, anger and grief that they “couldn’t see their way out of”. Core to the conflict was the decision making process, with the medical team believing in the importance of Mr. C’s participation in the process, nursing feeling unsure of Mr. C’s capacity to meaningfully participate, and the family’s desire to forgo surgery based on the massive quality of life changes a surgical approach would impose on Mr. C, particularly given the new finding of stroke and its consequent impact on his vision, hearing and equilibrium coupled with new information about the need for massive buttock debridement which would likely render him bed bound for life.

Mr. C. experienced profound thirst, but Diane had to restrict fluids because of Mr. C’s risk for aspiration. It was clear to her that liquids were the one thing he desperately wanted, and she desperately wanted to meet this need, particularly since he had been through so much, but she knew he had failed his speech and swallow consult, placing him at risk for aspiration. While limiting PO intake is common in nursing practice, this instance exemplified the overall conflict embedded within this patient’s care. Diane understood that both the family and the physicians knew the rationale for withholding fluids, but felt that both groups used words and gestures to send a different message to her and Mr. C, making her feel upset, frustrated and like the “bad guy”.

Diane described the final decision to forgo surgery as one crafted by many participants, including the patient, who indicated he wasn’t confident in his decision making capacity but was
100% confident in Charlene’s capacity to make the right decision for him, psychiatry, who assessed Mr. C as having full decision making capacity and fully aware that he would die without surgery, palliative care, the medical team and nursing. The ultimate result of achieving a decision with which all were comfortable took three full days. Diane described the inherent challenges associated with achieving this goal.

When Diane resumed responsibility for Mr. C’s nursing care, she realized both the depth and breadth of the team/family communication void and the need for her to serve in the role of interpreter. She discovered that both parties felt they were communicating clearly, but neither felt heard. Importantly, the team’s understanding of the plan was to wake Mr. C to engage him in the care planning process. Alternatively, it was the family’s impressions that Mr. C was being woken to allow “good byes” to be said, followed by a conversion to comfort measures only. Diane assumed an understanding had been reached when she observed family inquiring with Mr. C about goals of care, only to realize the family was doing so because they felt forced into this approach by the medical team. She quickly realized the family’s feelings of betrayal.

Diane’s interventions focused on assuring her presence during all subsequent conversations between providers and family members, employing careful listening and interpretation to assure clarity and understanding. She realized that “messages were not coming across’ without nursing presence. Diane provided constant and ongoing translation in all of the multiple provider/family meetings. Her impression was that, although delayed, the process’s ultimate success resulted from the family’s complete confidence in nursing’s devotion to achieving an outcome focused exclusively on Mr. C’s best interests.

…the family felt very confident and comfortable with the nursing care and I felt like even though they were at times unhappy with the physicians and with MGH in general, they felt that the nurses were doing everything that they could with the family’s and patient’s best interest in mind…
<table>
<thead>
<tr>
<th>Patient</th>
<th>RN</th>
<th>Patient</th>
<th>Medical Team</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>The patient was critically ill with shock due to sepsis</td>
<td>Diane spent the entire first day trying to keep him alive</td>
<td>The patient improved to the point of extubation, but could not discuss his necrotic extramities</td>
<td>Family’s crisis evolved as they grappled with decision making regarding amputations, ultimately deciding to pursue surgery while also worried that the patient would not want the amputations</td>
<td>Family experienced a “horrible” two week period of anger, frustration and grief</td>
</tr>
<tr>
<td>Diane established a goal of instituting CVV by the end of day one, but the system crashed shortly after starting the treatment; Diane was able to reinstate successfully</td>
<td>The patient was somewhat more stable at the end of day three but, even though his overall clinical outcome was unclear, it was clear to Diane that he would require hand/foot amputations</td>
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<td></td>
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</tbody>
</table>
Diane perceived this period as more exhausting than her first three days of patient care.

Medical team/family conflict regarding decision-making process.

Patient focused on profound thirst; Diane focused on preventing aspiration.

Diane served as patient/family/team translator.

Achieved consensus through translation.

Never got completely stuck, as can sometimes happen.

Despite ups and downs, headway was made.
Diane’s Response to the Pattern Analysis

The transmuted diagram of Diane’s narrative, beginning with the first three days of her care and culminating in the last three days of her care for Mr. C and his family was shared with Diane during the second interview, providing Diane the opportunity for reflection and clarification. Diane offered the following realizations.

A) The value of verbal engagement in fostering outcomes, and her willingness to become more interpersonally engaged with patients and families as her nursing practice expands.

Because I’ve never talked so much I don’t think in my entire career, and just trying to refocus the clinicians, the physicians, about what the family wanted, and what they were hearing, because what the doctors and what the family was hearing was not the same thing.

Because I mean, as far as taking care of him, he was relatively stable. Wound care and dialysis was pretty much all that he needed. So his needs were met sort of easily, and it was the needs of the family, and the need for a lot of communication, that was the primary…my primary role for these three shifts. I’ve never talked that much, ever, in the 10 years that I have been a nurse.

B) Although the process was very challenging, forward movement was achieved and inertia, which is a reality for some patients and families, was avoided.

Diane’s Pattern Analysis Summary

Reflecting on her narrative through its diagrammatic representation offered Diane an opportunity to realize and appreciate the situation’s profound impact on her professional development. Diane’s prior tendency to forgo indepth patient and family connections was challenged by the needs of this patient and his family. While she addressed these needs directly by serving in the role of translator, a role well embedded in this family’s pattern, her situational involvement including dialogue and translational bridging within the nurse/family relationship represented a choice point in the expansion of her consciousness to stage 4 of Young’s theory. As acknowledged by Diane, direct involvement towards goal achievement via dialogue and human
connectedness served as an antidote to the emerging conflict within the goals of care processes. Failure of goal achievement can occur without this degree of commitment, causing delays in tangible outcomes such as length of stay, but also potentially resulting in prolonged human suffering in the face of uncertainty. Diane noted the learning provided by this situation, and acknowledged the practice advancements afforded her by this opportunity. The pattern expression of the whole is represented by the theme” The Learned Value of Engagement in Achieving Nurse Interpreted Patient and Family Goals of Care Outcomes”.

Section Three

*Phase One: Summary*

Responses to the study’s two research questions illuminated both family member and registered nurse participant evolutionary stages, patterns and advancements towards consciousness expansion. Further, study data revealed integration between family member and registered nurse themes. The theoretical constructs of Newman’s Health as Expanding Consciousness coupled with Young’s Stages of Evolution were employed to more fully extrapolate participant pattern.

*Phase Two: Data Analysis within Family Member, Registered Nurse and Integrated Family Member/Registered Nurse Groups*

Responses within the family member and registered nurse group were dwelled upon and analyzed for the presence of recurrent themes. Employing Newman’s (1994) methodology as outlined in Chapter Three, themes reflecting both the experiences of families when a loved one was receiving care within a medical intensive care unit and the experiences of registered nurses providing care to these patients’ families were analyzed for repetitive elements.
Family Member Themes

Shared family member themes emerged and were clustered by commonalities. Presentation and discussion of these shared themes follows below.

1) Family members reassess their life goals during the critical illness experience

2) Family members experience comfort and experience easing of emotional burdens by being with the patient and involved in care processes

3) Family members experience increased awareness and increased freedom within Young’s Model by staying true to patients’ end of life choices and wishes

Family Members reassess their Life Goals during the Critical Illness Experience

The critical illness experience afforded opportunities for goal reflection among a cadre of family members. Achieving this outcome was multifactorial. It involved the seriousness of the event itself, the care environment’s family and relationship centered care provided within a philosophy of palliative and critical care integration, and participant/researcher dialogue.

Anna was deeply impacted by her husband’s serious illness and the need for aggressive life support measures. The bond within this husband/wife relationship and its positive influence on their successful management of prior life crises had recently become underappreciated in the face of day to day worries, and now was fractured due to Mr. A’s life threatening illness. The possibility of her husband’s death caused Anna to develop a renewed appreciation for the primary importance of friendship within their loving companionship. Additionally, she noted the significance of nursing’s approach, including a welcoming response to questions and unrestricted presence, as mechanisms that enhanced her successful recommitment to their valued friendship.

The importance of the family centered care environment is further reinforced through Anna’s
concern that she may have been unable to achieve this renewed perspective in a less family focused ICU.

Rose’s reflections during her daughter’s critical illness helped her achieve an awareness of neglected areas on which she planned to refocus. These included the importance of maintaining her own health, addressed by plans to reschedule missed health screening appointments. Further, she planned to reunite with her brother and sister, with whom relationships had been severed due to parental estrangement. Additionally, she recognized the life stressors she and her partner had been experiencing, including her father’s recent death. Planned interventions to address the emotional impact of these stressors included the need for both her and her partner to effectively mourn her father’s loss, and to seek Hospice assistance to achieve this goal.

Helena’s experience of her husband’s tick borne critical illness caused her to entertain possible lifestyle adjustments. These included limiting her husband’s outdoor work and subsequent tick exposure, a decision which would greatly impact the joy he achieved through being outdoors and helping her with master gardening. Alternatively, it may be necessary for them to make an even more dramatic change by moving to a new residence with a lesser risk for tick infestation. While Helena acknowledged that they have previously considered moving, she also noted that her husband has been less willing to do so than has she, given their current home’s easy access to running trails. Helena noted that she would wait for her husband to raise the topic, as it would signal his readiness for the discussion.
Family members experience comfort and experience easing of emotional burdens by being with the patient and involved in care processes

The critical illness experience was appreciated as burdensome for families. The degree of clinical severity caused uncertainty and fear among family members. These emotions were countered by family member observations of and participation in care components.

Ava noted the grave anticipatory fear she felt as she entered the patient/family meeting conducted to discuss her dad’s need for intubation. Yet, she appreciated the opportunity to directly observe her father’s participation in the discussion, and his ultimate informed decision to proceed with intubation. Further, she derived comfort from seeing his acknowledgement of her bedside presence, including his nodding and eyebrow movement. Ava, in reflecting on the meaning of being able to be present with her dad in his experience of critical illness, described it as making the situation “bearable” and preventing her from becoming “nuts”.

Linda acknowledged the full attention offered to her questions by the care team, and its impact on relieving any concerns about the care her loved one was receiving. Additionally, as the proxy and substitute decision maker, she noted the importance of information and its impact on the effectiveness of her substituted decision making. Linda also described how being fully informed helped her to feel comfortable leaving her loved one’s bedside. Staff knowledge, teamwork and unrestricted family presence were assessed by Linda as elements that countered family member feelings of chaos and stress.

The importance of participating in rounds was acknowledged, with participants ascribing unique values to the experience. Helena contrasted her need to remain clinically informed with her concern of becoming overwhelmed by medical information, with rounds serving as the perfect approach to this concern, as it blended a learning opportunity with subsequent clinician bedside
visits where questions were answered and medical language was interpreted. Helena described this as a “gift”.

As the caregiver of a daughter with complex medical needs, Rose was deeply concerned that her knowledge of her daughter’s care in the “foreign land” of the hospital would be misinterpreted. Rather, she was pleased to be welcomed by the MICU staff as a valuable source of information. Participating in rounds led to the discovery of a medication dosing error when she described a slight difference in her daughter’s level of alertness in response to the team’s inquiry about her daughter’s overall appearance. Rose was impressed with rounds, describing the process as a community of deeply caring individuals who were focused intently on one patient at a time.

While not typically considered a process of care, Rose’s experience in the family waiting room outlined the support she gleaned from the public gathering space. She described her transition from initially feeling overwhelmed in the waiting room to an appreciation of other family members as a caring community of strangers, and their positive impact on lessening her loneliness. This evolution occurred as individuals inquired about her daughter and shared their caring concern. Rose’s experience of isolation as the mother of a disabled child evaporated as she became an equal among strangers whose loved ones were also experiencing life threatening illnesses.

*Family members experience increased awareness and increased freedom within Young’s Model by staying true to patients’ end of life choices and wishes.*

Four of seven family members acknowledged their loved one’s pre established goals of care, and all had participated in the development of these plans. Despite their involvement, participants implemented their loved one’s end of life goals to varying degrees. The data demonstrates a connection between implementation of pre established goals of care and loved ones’ level of consciousness evolution.
Charlene, whose interview data analysis placed her in stage three of Young’s consciousness evolution model, experienced the most tumultuous decision making regarding her fiancée’s advanced directives implementation. His end of life goals, which they promulgated as a couple and which were informed by the experience of his father’s prolonged cardiac illness, included the desire to avoid prolonged dependence on life support technology. Yet, Charlene struggled with applying these general goals to the specific need for limb amputations currently faced by her loved one. Conversely, the registered nurse involved in navigating Charlene through her end of life decision making struggles clearly recognized that multiple limb amputations performed on a man who valued both his work as a truck driver and his hobby of lobster fishing would not be aligned with his goals of care.

Evelyn remained steadfastly supportive of her husband’s life goals, including his decision to reject liver transplantation due to deep concerns of living a post transplant life consumed by multiple medical problems. She described this decision as evolving from their marital commitment to full teamwork. This decision was applied to her husband’s clinical course on day one of their MICU admission through placement of a “do not resuscitate” (DNR) order. Evelyn was then faced with reversing the DNR order when her husband experienced a life threatening arrhythmia and the need for defibrillation. Her ultimate decision to reverse the DNR was accompanied by emotional distress. Evelyn’s registered nurse intervened to ease her emotional distress by acknowledging the constant change endemic to a critical care admission, and its impact on a surrogate’s end of life decision making. Data analysis from Evelyn’s interview data placed her in the forth stage of Young’s consciousness evolution model.

Information about Helena’s husband’s goals of care emanated from Irene, his registered nurse. She learned about their end of life planning through bedside conversations with family members,
and was impressed by the family’s detailed attention to this work. Irene was struck by the clarity with which Mr. Jones’ exact goals were known to his family, including his desire to avoid any long term mechanical support. She also admired the impact their son’s presence and support had on reinforcing Helena’s commitment to her husband’s goals of care. Helena’s interview data analysis placed her consciousness evolution at step five of Young’s model.

Max, whose interview data analysis also placed him at the fifth level of Young’s consciousness evolution, offered similar clarity and commitment towards his wife’s goals. Max described his dedication to her pre-established goals of care as emerging from their lifetime of mutual support. Max endorsed the decision to reintubate his wife, but with the caveat of doing only to determine if further medical treatments could help return her to her prior level of functioning. Max ultimately converted his wife’s status to comfort measures only once it was determined that she was failing to respond to further medical interventions.

Registered Nurse Themes

Shared registered nurse themes emerged and were clustered by commonalities. Presentation and discussion of these common themes follows below.

1) Registered nurses know patients more fully by interfacing with the family’s unique way of being

2) Registered nurse relationships with the family’s unique way of being enhances the meaning of professional nursing practice

3) Registered nurses ability to harmonize critical care and palliative care gives meaning to relationship based patient and family centered nursing care
Registered Nurses Know Patients More Fully by Interfacing with the Family’s Unique Way of Being

Technologic support for patients experiencing high acuity illnesses often requires the application of sedation and pharmacologic paralysis to achieve clinical stability. Additionally, some patients present with coma or other forms of altered mental status, including delirium. Together, this frequent phenomenon of either altered or absent mental status significantly limits the nurse/patient interpersonal connection. Study data reveals the positive impact gleaned from nursing’s interface with the family’s unique way of being.

Unlike the majority of MICU patients, Evelyn’s husband Frank was lucid throughout his MICU stay. This offered Grace, Frank’s MICU nurse, an opportunity to directly observe the loving language and gestures Frank and Evelyn shared, fostering Grace’s appreciation of the couple’s special relationship. Consequently, Grace developed a new awareness of the limitations inherent in understanding patients through unilateral information provided by family members.

Irene appreciated learning about Mr. Jones’ story through conversations with his family members. She contrasted this approach to the less direct approach of the “Get to Know Me” poster, another mechanism used in the MICU to achieve understanding of individual patient characteristics. Further, she noted the pleasure derived from learning about the patient via family member recollections.

Registered nurse relationships with the family’s unique way of being enhances the meaning of professional nursing practice

Family members are focused and engaged with their loved one’s experience of critical illness. Additionally, families share this involvement within the family unit. Information from this study
unveils inspirational nursing practice derived through direct observations of the family’s unique way of being.

Mr. A’s clinical instability during his second MICU admission, when Brenna provided the majority of his night shift nursing care, prevented her from having any direct patient communication. She learned of his pleasant nature through information shared with her by nurse colleagues. Yet, despite the absence of a direct patient interface, Brenna experienced profound joy in caring for him due, in part, to her observation of and admiration for the wonderful ways in which the family connected with each other.

Grace’s practice of encouraging family meetings is intrinsic to her nursing care. However, participating in Frank’s family meeting, and the opportunity to observe the love embedded within Frank and Evelyn’s relationship, caused Grace to develop a deeper emotional connection than is common in her practice. She was moved to both engage more fully with this couple, and to offer her most excellent practice.

Mr. Jones’ family shared with Irene his devotion to physical fitness, including running and participation in marathons and senior Olympic events. Irene also learned of the family’s attention to advanced care planning, their knowledge of Mr. Jones’ exact wishes, and their commitment to implementing these pre established goals of care. Irene’s determination for nursing care excellence became even more pronounced as she learned additional details of Mr. Jones’s life.

Registered nurses ability to harmonize critical care and palliative care gives meaning to relationship based patient and family centered nursing care

The experience of critical illness is burdensome for patients and their loved ones. Core elements within the palliative care model (Table 2-1) integrate multidimensional processes, including comprehensive patient and family centered care, to help relieve this distress. These study results
disclose critical care nursing’s fluid integration of a relationship based critical and palliative care model.

Barbara’s care of Mr. A included attention to both patient and family care needs. She established and implemented the goal of bed to chair ambulation to help facilitate the patient’s recovery. Additionally, she welcomed Mr. A’s daughter, encouraged her various questions, and assured her that her questions were welcomed.

Brenna focused on supporting Mr. A’s family through their experience of his second and ultimately fatal diagnosis of ARDS, while concomitantly managing his clinical needs. Brenna’s narrative focused on the strategies she employed to enhance the family’s coping, including provision of unlimited bedside access to both promote family comfort with the foreign ICU environment and the creation of opportunities for nurse/family dialogue, and family inclusion in the numerous clinical interventions employed to treat Mr. A’s ARDS. Further, she directed her ongoing assessments to include evaluation of these approaches on the family’s coping mechanisms.

Diane’s care priorities for Mr. C. shifted from intently patient focused to intensively family focused. The intensity of Mr. C’s clinical needs during the initial phase of his MICU admission was all consuming. Subsequently, as she provided nursing care during his final days of life, she focused almost exclusively on his family’s coping needs, helping to negotiate a resolution to the conflict which had emerged between family members and the medical staff.

Irene’s provision of Mr. Jones’ care transitioned from patient to family centered during the first two days of his MICU admission. Similar to Diane’s experience, Irene’s first night shift was devoted to the provision of life sustaining measures to achieve hemodynamic stability in a patient experiencing shock due to sepsis. Irene connected only minimally with the family on this first day,
primarily through the provision of telephone updates to the patient’s wife, who phoned from her hotel room. Irene’s narrative also highlighted her knowledge of complex hemodynamics and their patient impact, and the nursing advocacy required to achieve physician approval to employ an effective intervention. Mr. Jones’ clinical improvement on day two provided her the opportunity to engage with and provide a supportive relationship for Mr. Jones’ family. She gleaned an understanding of the patient’s startle response to physical repositioning through information family shared about his prior experience with PTSD.

Grace facilitated a family meeting on day one of Frank’s MICU admission and, given his lucidity and desire to participate, she assured both patient and family inclusion in the discussion. The meeting concluded with a consensus based decision to initially pursue an aggressive treatment plan while retaining the pre established decision to forgo resuscitation. Grace remained both clinically and interpersonally connected as the patient experienced a rapid clinical deterioration.

Stephanie simultaneously understood both Rose’s expertise as her daughter’s primary care provider and the vast differences between primary and critical care, with which Rose had little experience. This appreciation helped her to recognize Rose’s misconceptions about the differences between endotracheal tubes and tracheostomies, for which she provided reassuring, educationally based information. She successfully engaged and distracted Rose during her daughter’s intubation by encouraging completion of the “Get to Know Me” poster, allowing Rose to focus on sharing components of her daughter’s life with the clinical team while directing Stephanie’s attention towards the heightened clinical intensity accompanying intubation. Rose welcomed and derived comfort from Stephanie’s suggestion of a chaplaincy consult to assist her with her experience of grief resulting from her recent father’s death.
Integrated Family/Registered Nurse Themes

Integrated patient/family themes were clustered by commonalities. Presentation and discussion of these shared themes follows below.

1) The intentional presence of the nurse grounded in relationship with patients and families brings comfort to both the nurse and patient/family and gives personal meaning to the experience for both groups

2) Creating opportunities for open dialogue with families and nurses around issues affecting the critical care of patients is a source of comfort, relief from suffering and has the potential to develop new insights about the experience and its meaning in their lives

3) The relationship between the family, nurse and patient during a critical hospitalization can harmonize critical care and palliative care and give new meaning to relationship based patient and family centered care

The intentional presence of the nurse grounded in relationship with patients and families brings comfort to both the nurse and patient/family and gives personal meaning to the experience for both groups

Nurses were comforted by their experiences of intentional presence. Brenna’s experience of personal meaning emerged from her admiration of the wonderful ways in which the patient’s family members treated each other, and served as one reason she “loved” providing care to the patient and his family. Irene had a similar experience of being comforted and touched by the patient and family’s gift of realistic decision making. Barbara’s remarkable presence included welcoming the patient’s engagement in his care, his daughter’s questions and his son’s phone call and, further, she was comforted by the patient’s daughter’s bedside engagement and the caring embedded in her thoughtful questions.
Grace advanced from a compassionate nurse to an intentionally present nurse as she developed and sustained her patient and family connectedness during the patient’s rapid clinical decline. Diane’s intentional presence fostered the family’s trust in the discipline of nursing as one that was and would continue to be completely focused on the patient’s best interest. Further, Diane’s actions prevented a languishing inertia for the patient and family through her commitment to advancing the process of conflict resolution and decision making.

Creating opportunities for open dialogue with families and nurses around issues affecting the critical care of patients is a source of comfort, relief from suffering and has the potential to develop new insights about the experience and its meaning in their lives.

Family awareness and understanding of their loved one’s condition was soothing, buffered anguish and protected emotional integrity. Linda noted the significant impact open dialogue had on her increasing sense of confidence with the care team, and the ways this approach eased any worries she may have had about posing questions. Indeed, this positively impacted her experience within the substitute decision maker role, leading to the elimination of doubt, uncertainty or stress within her decision making processes. Open access to her loved one and information about her loved one’s care allowed for an unfolding comfort which transitioned her life from chaos to order.

Ava prolifically noted the value open communication had on her psychological well being. She discussed the valuable role information played in helping her retain a sense of control. Further, Ava noted the real possibility of experiencing psychological degradation, but believed this was prevented by being able to partner with her dad during this life crisis event.
The relationship between the family, nurse and patient during a critical hospitalization can harmonize critical care and palliative care and give new meaning to relationship based patient and family centered care.

The importance and significance of interpersonal connectedness emerged through narrative analysis. The connection between Stephanie and Rose, her patient’s mom, illuminated palpable characteristics of relationship based patient and family centered care. Stephanie was able to dissipate mom’s unnecessary worries by correcting her misconceptions about the endotracheal tube, tracheostomy and tracheostomy care needs. Further, having Rose complete the “Get to Know Me” poster during her daughter’s intubation served not only as a distraction but also provided Rose an opportunity to joyously demonstrate her daughter’s capabilities to the entire care team. Stephanie’s reflection on pre-established expectations among those whose loved ones are transferred from less acute facilities offers understanding and appreciation of the pressures experienced within the tertiary provider role, and the impact this may have on nursing’s personal accountability towards meeting loved one’s hopeful expectations.

Brenna’s connections with the patient/family dyad integrated critical care nursing with palliative care components and expanded understanding beyond characteristic elements of relationship based and family centered care. The family was comforted on multiple levels including a welcoming bedside presence and the provision of information, all of which were provided within an atmosphere of warmth, caring and genuine humanity. Brenna offered remarkable sensitivity to the individuality of each family member.
Figure 5-1

Transformative Recovery
CHAPTER FIVE

Discussion, Significance, Implications and Limitations

The purpose of this study was to illuminate both the experiences of ICU family members whose loved ones received relationship based nursing care within an integrated palliative and critical care ICU and the experiences of registered nurses practicing in this intensive care unit. These experiences, which became understood through participant/researcher reflections, were diagrammatically represented as patterns and discussed with participants to allow for the unfolding of insight and human transformation. This chapter will address study results in relation to existing findings, and will highlight any unique discoveries. Significance and implications for the development of nursing theory, research, practice and education will be presented, as will health care policy implications and study limitations. The study’s contributions towards possible empiric expansion of existing literature will also be addressed.

Introduction

Connections between philosophically based theory and its associated research methods, or scientific approaches to knowledge acquisition, are essential for envisioning nursing practice (Willis & Grace, 2001). Margaret Newman’s nursing theory of Health as Expanding Consciousness encompasses a philosophic belief in the integrity of an inseparable human/environmental wholeness. Consciousness serves as the informational capacity of this whole, with health revealed throughout its evolving pattern (Newman, 2008). Belief in indivisibility between persons and their environments is synergistically aligned with hermeneutic phenomenology’s focus on the integrated experiences of person and environment (Heidegger, 1962). Newman has described the theory’s scientific method as praxis, or the interface of theory, research and practice, guided by a priori theory, and exemplified through a mutual process of
narrative dialogue based on helping intentionality, followed by diagrammatic conversion of
dialogue into pattern whose goal, when shared with participants, is achievement of transformative
health expansion through realization of new ways of knowing and being (Newman, 2008).

Elements within Newman’s health as expanding consciousness are supported by a priori
theoretical formulations including those of underlying pattern, growth following disruption and
consciousness evolution. Bohm’s (1980) theory of implicate order professes an underlying, or
implicate order, unencumbered by space or time, representing all observable manifestations,
including health. Prigogine’s work posits the value of a system’s disorganization in redirecting
itself towards a higher level of organization (Prigogine, 1976; Prigogine & Stengers, 1984).
Young’s (1976) stages of consciousness expansion are aimed at achieving a level of freedom and
growth extending beyond the barriers of space and time.

Individuality can be appreciated in the unique ways persons respond to opportunities for choice,
serving as a point of differentiation as individuals select alternate activities and directions in
response to periods of flux (Newman, 2008). Previously employed solutions to a new episode of
instability, or flux, are unsuccessful at addressing the current life event, requiring an alternate
approach to life choices; symmetry is lost to asymmetry. Newman (2008) describes the decision to
move on as asymmetrical and, when occurring in the nurse/patient relationship, asymmetry serves
as a mechanism to achieve growth and transcendence. Explication of implicate through pattern
development and client dialogue provides insight and offers a platform for achieving health
expansion.

Individual Family Member Patterns

Individuals demonstrated variability in their capacity to recognize pattern and plan new
approaches to facilitate personal growth and transcendence. Insights among those able to recognize
pattern were relationship based. This finding is congruent with that discovered during exploration of meaning among coronary artery disease patients, some of whom appreciated the importance of enhancing family member relationships (Newman & Moch, 1991). Categories of relationship included recognition of the importance of relationship with others, and recognition of the need to nurture existing relationships.

Both Anna and Max articulated connections between their spouse’s critical illness and the importance of life relationships. Anna noted the positive impact that prior life adversities had on strengthening both marital and mother/daughter bonds. Max attributed his capacity to implement his wife’s previously established end of life goals to their life long pattern of mutual support.

The need to nurture existing relationships was also appreciated. Anna achieved renewed understanding of the primary importance of her spousal relationship through her experiences with the unit’s integrated palliative/critical care processes and its relationship based nursing care, including unrestricted bedside presence and staff’s openness to questions. Rose was also able to employ pattern to recognize a need to reunite with her brother and sister, and to refocus on the relationship she shared with her long term partner.

Among those unable to achieve pattern recognition, participants included either those too encumbered by their loved one’s critical illness to be able to reflect on the diagrammed pattern construal, or those who admired the construal but were not able to achieve any discernable forward growth of consciousness at the time of reflection. The former group participants were completely distracted by the intensity of their loved one’s illness and either could not meet for the second interview and review of pattern construal or only allowed themselves a brief reprieve from their bedside vigil to quickly review the findings, both of which reflect the enormous family member burden of critical illness. The later group seemed genuinely pleased with the pattern construal, and
agreed with both the contents and timeline, but did not achieve any recognition of pattern. In fact, one participant stated that she would “cherish” the document, which was warmly welcomed as a gift by both the client and researcher, and considered a meaningful outcome of the encounter. Failure to achieve pattern recognition has been addressed throughout Newman’s work as a meaningful representation of the absence of personal pattern.

Family Member Themes

Thematic similarities were noted among aggregated family participants. The following themes were appreciated 1) the critical illness experience facilitated family member reassessment of life goals 2) being with the patient and involved in their loved one’s care processes provided families comfort and lessened their emotional burdens and 3) families with higher levels of consciousness expansion as described within Young’s model remained true to their loved one’s end of life choices and wishes. Discussion of these findings follows.

Family Member Theme One

Family member reassessment of life goals often led to discoveries about the importance of relationships, as noted within the above discussion of individual family member patterns, including acknowledgment of the importance of past relationships and plans for re-establishing relationships during their loved one’s hoped for recovery. Further, similarities between this finding and that of prior authors have been mentioned. Other participants focused on either themselves or their lifestyle. Rose appreciated the importance of her own health, recognizing the need to refocus on health promotion behaviors such as annual mammograms, etc. Helena was actively considering the need to either limit outdoor activities or move to a home whose location posed less risk for acquiring tick borne illnesses, but decided to allow her husband to broach the topic, signaling his readiness for discussion. These additional goals represent participants’ exploration of new ways of
living life and, too, resonate with Newman and Moch’s (1991) results demonstrating a desire to discover a new way of life among a cohort of coronary artery disease patients.

**Family Member Theme Two**

Family member presence and involvement in care processes emerged as important elements in achieving family members’ comfort and alleviation of the emotional burdens of critical illness. Family members’ desire for proximity and presence has been appreciated since the mid 1970s, and involvement in care processes has been widely espoused. Yet, clarity around the meaning embedded within these elements has been lacking. The following results shed light on family member participants’ lived experiences.

Ava was consumed with anticipatory fear as she prepared to participate in the family meeting discussion about her dad’s intubation. However, her fear was lessened by observing her dad’s participation in the actual decision. Then, once intubated, she again was comforted by seeing her dad interact with her, albeit nonverbally due to the endotracheal tube. Proximity allowed Ava direct observation of her dad’s decisions and behaviors, sustaining the integrity of their father/daughter relationship. Similarly, Anna reported that unrestricted bedside access helped her to re-evaluate the importance of the friendship she shared with her husband.

Involvement in processes of care was noted by numerous participants. Linda described the value of information in relieving her concerns, but specifically addressed the engagement of care providers, noting their full attention to her questions. Helena experienced rounds as a way for her to access information without becoming overwhelmed and further valued clinicians’ clarifications at the conclusion of rounds. Rose interpreted the rounding process as a community of caring providers focused on one patient at a time which, for Rose, helped her feel welcomed and valued as a source of information about her daughter’s complex needs. Present throughout all of these
narratives is the way in which each participant’s involvement in their loved one’s care interfaced with their needs as individuals, and the associated caring, human connections embedded within these care processes.

Suggestions of relational connections between experiences, coping and stress have been reported among ICU loved ones (Paul & Rattray, 2008). More recently, the compilation of family member emotional responses identified as the post intensive care syndrome – family (PICS-F) has been described, with two suggested prevention strategies including a) the way in which providers communicate with family members and b) the inclusion of families in both care and decision making (Davidson, Jones & Bienvenu, 2012). Application of the unitary-transformative paradigm and its praxis research methodology among ICU family members has revealed data supporting these two elements as salient mechanisms in our armamentarium of strategies to assist family members’ successfully manage the burden of a loved one’s critical illness. Further, this study’s praxis methodology reveals information highlighting proximity’s value in sustaining family integrity through unifying human connectedness despite the experience of profound critical illness. Additionally, it highlights the value of relationship, seen as an unbroken wholeness between the care team and family members, which allows space for family members’ unique ways of being to be welcomed.

Nursing communication emerged throughout this study as a prominent element of relationship based and family centered nursing care. Specific components of this overarching approach include a) encouraging family presence, b) normalizing the environment and its requisite audio and visual stimuli and c) valuing family presence by employing a welcoming approach. Ways in which this may be accomplished have been outlined as a sequential process which, in addition to the above, includes titrating information, assessing family member assimilation of the information, and
expanding on the information, while concomitantly assessing for evidence of anxiety and its influence on the family’s capacity to absorb the provided information.

Family member inclusiveness has also been revealed throughout the narrative descriptions. Supported and developed through the philosophical approach of an integrated palliative and critical care environment, the unit’s focus includes various mechanisms to assure family involvement in decision making. Both family members and registered nurses have noted the importance of these elements including information sharing, formal and informal family meetings, family presence on rounds and the “Get to Know Me” poster.

*Family Member Theme Three*

Care should be provided in ways which are aligned with patients’ goals and values. This is especially true in the ICU, given the high risk for morbidity and mortality. Further, goals and values become nuanced in the ICU by the highly fluid and uncertain nature of critical illness, enunciating the importance of family member commitment to patient wishes.

Four of seven family members participated in their loved one’s creation of pre-established health care goals. Yet, within the evolution of their loved one’s illness, variation in application of these care goals emerged. Data from this study reveal a connection between family members’ level of consciousness evolution within Young’s model and their capacity to remain true to the loved one’s end of life choices and wishes, with those at a higher level of consciousness able to maintain a steadfast commitment to their loved one’s desires. Family member participants demonstrating behaviors reflective of stage five of Young’s theory of human evolution, which serves as a point of ego transcendence, were consistently able to remain steadfast to their loved one’s goals of care decisions.
Physiologic impairment greatly limits critically ill patients’ ability to participate in their end of life decision making. Substituted decisions of family members or other loved ones are often impacted by various contextual and process factors, all of which may limit achievement of consensus based decisions (Heyland et al, 2006). This study is the first to establish an interface between levels of consciousness and end of life goals. Implications for further research and practice will be addressed below.

Individual Registered Nurse Patterns

All registered nurses except one failed to appreciate any further realizations during review of the diagrammatic representation of their narrative. The registered nurse who did recognize pattern was involved in a transformational situation which impacted her future nursing practice. This finding is in keeping with studies demonstrating enhanced responses to pattern recognition during periods of heightened turbulence (Newman, 2008). However, the absence of transformation through pattern recognition among this cadre of critical care nurses deserves further investigation.

Registered Nurse Themes

Thematic similarities were noted among aggregated registered nurse participants. The following themes were appreciated 1) registered nurses know patients more fully by interfacing with the family’s unique way of being 2) registered nurse observations of the family’s unique way of being enhances professional nursing practice 3) registered nurses ability to harmonize critical care and palliative care enhances the meaning of relationship based patient and family centered nursing care. Discussion of these findings follows.

Registered Nurse Theme One

Nurses are commonly unable to communicate with their critically ill patients. Compensatory mechanisms for this barrier include the “Get to Know Me” poster, which provides written
information about the patient and family. This theme illuminates the value nurses place on direct engagement with families to enhance their knowing of patients and their loved ones and further, identifies challenges to discerning a more fully developed understanding of the patient as a person and the patient/family interface. Within this study, nursing’s capacity to directly understand the patient and family’s unique way of being assisted in the extrapolation of embedded meaning within goals of care decisions, fostering appreciation of and direction for informed decision making.

Registered Nurse Theme Two

Various studies have reported registered nurse imposed visiting limitations for multifactorial reasons including the unit’s structural and size limitations, issues of power and control and family member engagement of nursing time intended for patient care (Chesla, 1996; Hupcey, 1998; Plowright, 1998). Notably, the above referenced literature was published twenty years following identification of the importance of family member proximity to critically ill loved ones, suggesting major delays in the implementation of important research findings. Registered nurses in this study were inspired to provide their best care by allowing the family’s unique ways of being to unfold at the bedside and, by doing so and observing these elements directly, achieved feelings of joyful participation in the caregiving experience, enhanced engagement with the patient and loved one and a determined practice excellence.

Registered Nurse Theme Three

These narrative accounts offer a glimpse into the fluidity with which the study’s registered nurses harmonized care directed at both effective patient rescue from and management of physiologic alterations of critical illness while simultaneously attending to the healing processes embedded within the practices of relationship based nursing infused with palliative care elements.
Encapsulated within this harmonization is ongoing disruption impacting patients and their loved ones which, according to Newman (2008), provide growth opportunities. An asymmetrical nurse/family relationship is comprised of growth and transcendence driven by additional information and insight, which ultimately expands consciousness (Newman, 2008).

Asymmetrical nursing practice as described through this theme reveals numerous episodes of nurse/family member dialogue regarding the patient’s clinical status, response to interventions and the influential impact of these clinical changes on ultimate patient outcome that, because of family member bedside proximity, occurs within the moment and prevents delays in information sharing. The HEC philosophic lens via its praxis methodology reveals family member awareness and insight may result directly from the harmonization of critical and palliative care within a relationship based patient and family centered nursing care environment. Reframed, it suggests that enhancement of our family members’ health may be directly attributed to the substantive practice elements of communication and inclusion in decision making. While anecdotal evidence of enhanced MICU family member wellbeing exists on various fronts, including infrequent ethics consultation requests and positive family member feedback, no confirmatory data linking the care model to outcomes is available, and serves as an area for future research.

*Integrated Family/Registered Nurse Themes*

Further exploration of data elements led to an appreciation of the interface between family members and registered nurses. The following three themes emerged from this discovery, including 1) the intentional presence of the nurse grounded in relationship with patients and families brings comfort to both nurse and patient/family and gives personal meaning to the experience for both groups 2) creating opportunities for open dialogue with families and nurses around issues affecting the critical care of patients is a source of comfort, relief from suffering and
has the potential to develop new insights about the experience and its meaning in their lives. 3) the relationship between family, nurse and patient during a critical hospitalization can harmonize critical care and palliative care and give new meaning to relationship based patient and family centered care. Additional discussion follows.

*The intentional presence of the nurse grounded in relationship with patients and families brings comfort to both nurse and patient/family and gives personal meaning to the experience for both groups.*

Relationships among nurses and family members emerged through consistent employment of intentional presence, revealing nursing’s deep and ongoing alignment with patients and families despite a wide array of needs and lived experiences. Further, family members authentically revealed the beauty embedded within their unique ways of being. Together, both intentional presence and authentic revelation resulted in mutual appreciation and harmonious reciprocity, fostering human engagement within the patient/family dyad and nurse.

*Creating opportunities for open dialogue with families and nurses around issues affecting the critical care of patients is a source of comfort, relief from suffering and has the potential to develop new insights about the experience and its meaning in their lives.*

Scientific exploration of ICU family experiences has evolved historically from descriptions of family member proximity and information to the contemporary categorization of Postintensive Care Syndrome-Family, termed to encapsulate the array of possible emotional distress occurring within ICU family members. Endemic within this interfaced family/nurse theme is the potential for new understanding offered through its paradigmatic reframing of open dialogue to a primary intervention. Triangulated integration of patient/family and nurse through open dialogue focused on their critically ill loved one reconceptualizes former issues including bedside proximity and
information sharing in ways that highlight open dialogue as a key nursing intervention, which may soothe fears, buffer anguish and both preserve and protect family emotional integrity, all of which may help to foster human growth within and subsequent to the experience of a loved one’s critical illness.

*The relationship between family, nurse and patient during a critical hospitalization can harmonize critical care and palliative care and give new meaning to relationship based patient and family centered care*

This integrated theme offers a unique lens through which to view the phenomenon of critical and palliative care integration, as it couples critical care nursing’s focus on physiologic patient rescue with human relationships embedded among the nurse and patient/family. Further, it alters the perception that critical care and palliative care integration offer opportunities for relationship building among nurses and patients/families to a vision of the relationship being primary and, when both patient based and family centered, fostering critical and palliative harmonization through relationship. Evolution of relationship based and family centered care has evolved throughout this study to include attention to palliative care elements including goals and preferences, appreciation of and attention to the bereavement period, conversion from a focused to a comprehensive multidimensional assessment, information sharing and active listening and attention to relief of suffering from illness related burdens.
Significance

This study describes the exploration of critical care family members and the registered nurses providing care to their loved ones. The study is significant as it represents the first application of Newman’s theory of Health as Expanding Consciousness within the critical care arena. Further, it is unique in that it applies the praxis methodology to both family members and registered nurses caring for their loved ones. As such, it allows for the descriptive unfolding of engagement among families and registered nurses, obtained through formulation of pattern and its potential for recognition, understanding and subsequent expansion of health, or consciousness, and thematic analysis among family members and registered nurses. Accordingly, as a result of the methodology’s capacity to illuminate components within the engagement of families and registered nurses, findings have emerged suggestive of elements within both the cultural and structural aspects of an intensive care unit that successfully facilitate the harmonization of palliative and critical care with relationship based patient and family centered nursing care.

Results from this study are also significant in that the unique application of the praxis methodology illuminates these ICU elements in ways that afford new understanding of their value and meaning as an integrated entity, rather than as distinctly separate elements. Extant critical care literature has, to date, employed reductionist methods to evaluate family member experiences and explore the impact of recommended interventions. This study, emerging from the unitary-transformative paradigm of nursing research, offers knowledge that both includes and transcends that realized through particulate-deterministic and interactive-integrative perspectives (Newman, 2008). Accordingly, it expands beyond the reductionist approach to appreciate transformative approaches to understanding family member experiences and directed interventions through
pattern recognition. As suggested by Pharris (2002) and confirmed through these results, HEC reveals ways for nurses to be in relationships with others.

Need to continue with final edits starting here

Implications

*Nursing Theory Development*

The theory of facilitated sense making (Davidson, 2010) is the only middle range theory currently available to guide critical care nursing interventions. The theory’s goal is to facilitate the family’s capacity to make sense of the critical illness and their desire to perform caregiving activities during time spent with loved ones. Specific elements of nursing care directed at preventing family members’ psychological adversity by supporting their adaptation and emotional health have been previously outlined in chapter two. However, results from this current study suggest the necessity of an alternate theoretical formulation. Praxis methodology has revealed the essentiality of a relationship based patient and family centered care environment integrated within a harmonized palliative and critical care setting as both structure and process elements which enhance flourishing and alleviate human suffering among both critical care family members and critical care registered nurses.

In a scientific review of knowledge as problem solving, Rodgers (2007) highlights Toulmin’s believe that problems reflect the net negative between disciplinary goals and current intellectual capabilities. As stated earlier, nursing goals include the alleviation of human suffering and promotion of human flourishing. Further, these goals are recognized for their ethical benefit in producing human good (Willis & Grace, 2011). To this end, creation of a facilitated critical care family wellbeing theory is proposed, with the goal of facilitating family wellbeing employing the role of asymmetrical nurse/patient relationships to promote awareness and growth within a patient
and family centered environment that harmonically integrates palliative and critical care practices. Development of a theoretical foundation for the structural and process elements required to promote family wellbeing is a critical first step in the creation and scientific verification of practice enhancement methods focused on alleviation of suffering and promotion of family flourishing within the context of devastating critical illness.

This study has uniquely applied Health as Expanding Consciousness to two participant groups, including family members and registered nurses providing care to critically ill loved ones. As application to two participant groups has not previously been employed, it is possible that data analysis could be further triangulated to account for the presence of parallel data sources. This could include a blending of a patient’s family member and registered nurse themes, with the goal of visualizing their unique integration in the setting of an individual patient. An example of data integration among the first participant group which included Mr. A’s wife Anna, his daughter Ava, registered nurse Barbara and registered nurse Brenna is proposed below. It begins with individual family member themes, is followed by individual registered nurses themes, then moves to an integration of family member themes and registered nurse themes and, finally, concludes with an integration of all themes into a single thematic formulation.

Anna’s theme: Sustaining Strength and Achieving Understanding in the Face of Life Crisis Events by Engaging in Supportive Relationships with Family and Nursing Staff.

The bonding within this husband/wife relationship and its positive influence on their management of prior life crisis experiences was now fractured as a result of Mr. A’s unexpected critical illness. Anna described emotional reactions including fear of loss, uncertainty and anxiety. Yet, she achieved consciousness expansion through recognition of the primary importance of the friendship within their loving companionship. Further, she attributed this to a combination of
unrestricted bedside access, and both nursing’s sincere interest in her questions and their inclusion of family as nursing care recipients.


   Ava experienced numerous emotions in response to her father’s unexpected critical illness, which also severed their close father/daughter relationship. She described feelings of fear, loss of control, worry and desperation. Countering these were care team actions including the invitation to participate in the informed decision making process surrounding her father’s intubation, unrestricted bedside access and its impact both on directly observing her father’s nonverbal responses and the opportunity for achieving a sense of control through questioning and information processing.

   Barbara’s theme: Limiting the Crisis through Caring and Information Sharing.

   Barbara illuminated her care as family centered. She integrated direct physical care to Mr. A. with elements of family centeredness offered to them as a father/daughter dyad. Barbara encouraged Ava’s presence, welcomed and was receptive to her questions and normalized information sharing as a part of her nursing practice. Despite working with them for only eight hours, she developed an admiration for the family’s personal characteristics and the quality of Ava’s questions.

   Brenna’s theme: Developing and Sustaining Family Consciousness Expansion through Presence and Information Sharing.

   Brenna’s engagement with this family led to her deep appreciation of their mutual love. Similar to employing clinical observations in the provision of patient specific care, she used interpersonal
observations to craft a family centered approach. Brenna acknowledged the importance of family connectedness, sustaining it throughout the remainder of the hospitalization. She assessed their responses to family bedside presence, teaching, and normalization, expanding these to more advanced levels as she recognized their positive impact on family coping. Brenna noted the value of direct observation on the family’s capacity to acknowledge clinical futility.

*Thematic analysis among Mr. A’s family members*

Theme: Family Centered Care is valued by Family Members for its Impact on Lessening Family Members’ Emotional Distress during Critical Illness

Anna and Ava feared the loss of their meaningful husband/wife and father/daughter relationships with Mr. A. They articulated their emotional distress, highlighting feelings which were both similar and individually unique. Further, they described the importance and value of nursing’s family centered interventions in their lived experiences of a loved one’s critical illness.

*Thematic analysis among Mr. A’s registered nurses*

Theme: ICU Family Centered Care is individualized through Understanding of Family Member Responses to Interventions

Barbara and Brenna normalized nursing practice as inclusive of both patients and families. Additionally, they noted specific components of their family centered approach. Brenna’s ongoing participation as a care team member provided the opportunity to understand her sequential application of family centered strategies and assessments used to determine their impact on family coping.

*Thematic analysis among Mr. A’s family members and his registered nurses*

Integrated Theme: Nursing’s Employment of Family Centered Care Strategies Preserves or Expands Family Member Emotional Wellbeing
Nursing sustained the loving bonds within this family. Although unable to return the family to their pre illness level of intactness, nursing’s use of family presence allowed for family proximity and both verbal and nonverbal communication with Mr. A. Application of family centeredness offered uniquely important outcomes for these family members. Ava’s narrative reveals its impact on preserving and stabilizing her emotional wellbeing. Anna described her achievement of consciousness expansion and personal growth to Young’s forth level of consciousness evolution. Together, the important impact of family centered care can be observed in the emotional integrity/emotional growth observed within this loving family’s narratives.

_Nursing Research_

The literature is replete with recommendations focused on providing ICU family care that is patient centered, family supportive, and inclusive of shared decision making. Yet limited advances have been achieved in this important arena. Expansion of this study is now suggested as a mechanism for furthering study findings in ways that may foster family member wellbeing.

Family member themes have been stated propositionally to allow for further scientific exploration. Key to further understanding is both validation of these themes and assessment of findings in relation to existing data, including family member satisfaction and psychological burdens. Areas for deeper investigation include a determination of the impact of consciousness enhancement on levels of both family member satisfaction and emotional symptoms including anxiety, depression, PTSD and complicated grief. Additionally, given the statistically significant relationship noted between family members’ trait anxiety, depression severity and development of PTSD (Paparrigopoulos et al, 2006), offering the HEC approach to those with positive trait anxiety scores could also be explored. These suggestions are focused on the need to provide ethically...
directed nursing care aimed at alleviating suffering. Further, its integrated approach is in keeping with Newman’s (2008) suggestion that a combination of analytical and 

Endo (1998) and Kiser-Larson (2002) discovered enhanced capacity to achieve insight among individuals experiencing a tumultuous situation. However, this study demonstrates challenges with achieving insight among a population of ICU family members, due partly to the burden imposed by a loved one’s illness. While some were too distressed by their loved one’s clinical instability to participate in the second interview, others prematurely concluded the second interview to quickly return to their loved one’s bedside. These findings suggest the impact of a loved one’s critical illness may be more than tumultuous and may, instead, represent profound distress among some families. These findings also allude to the need to scientifically evaluate timing of the intervention, suggesting that it may be more beneficial for family member participants if done at a time of clinical recovery, either inside or outside of the ICU, or may perhaps be even more efficacious if family members are engaged following discharge, such as may be possible through family involvement in an ICU survivors’ clinic or post discharge home program.

It will also be necessary to engage in more long term assessment of family members. While informative, this study’s data represents only one point in time, and does not provide the capacity to understand family member experiences during the duration of the critical illness. Additionally, practice enhancements could be generated through a deeper understanding of family experiences beyond the conclusion of the critical illness episode. Further, while family members were often eager to engage in study participation, recruitment was hampered by family members’ frequent experience of sudden changes in their loved one’s condition. While common in an intensive care, its impact on family member recruitment was underappreciated by this researcher. Together, these
suggest the benefit of more longitudinal exploration of family members’ experiences of meaning during their loved one’s entire episode of illness, including both the critical period and its sequela.

Results noting connections between participants degree of consciousness expansion within Young’s model of human evolution and the capacity to remain committed to a loved one’s previously established goals of care also requires further examination. Preventing family member vacillation from prior goals is one of the most challenging but often occurring events within the ICU decision making process, and is influenced bi directionally both by pressure directed towards loved ones by the care team and family member indecision. Validation of these results, consideration of additional or alternate methods which may advance loved ones’ human development and exploration of the MICU care environment’s impact on human evolution will be important next steps.

Registered nurse themes have similarly been propositionally stated for further exploration. In addition to further scientific exploration focused on validating study themes, it will also be important to understand the absence of pattern recognition among all but one of the study participants. One possibility is that registered nurses practicing within the critical care environment do not perceive a patient’s critical illness as turbulent, given the expectation of elevated patient acuity within the ICU and, as such, are less inclined to achieve pattern recognition.

Another area of further investigation is the finding of a connection between family member development within Young’s spectrum of consciousness and their commitment to pre established end of life goals. Families often falter in their steadfast dedication to goals for various reasons, including provider infusion of hope, alternate opinions voiced by loved ones who did not participate in the original decision making process, financial considerations, etc. While it is recognized that this is an initial finding, and required further understanding, it does suggest a
mechanism by which patients’ wishes can be more fully implemented during the critical illness experience.

The integrated family/registered nurse themes offer a novel area for scientific exploration. Notable within each of the three integrated themes is the paramount importance of nurse and patient/family relationship, implemented through intentional presence and open dialogue. Both family member and registered nurse narratives acknowledge the tremendous value afforded by a relationship based patient and family centered care model. Further investigation of the phenomenon of nurse and patient/family in relationship through intentional presence and open dialogue could significantly illuminate impact on personal meaning and the acquisition of new insights during critical illness, both of which offer the capacity for human insight and growth.

While the need to establish effective family communication and inclusion approaches is paramount, and additional studies as proposed are meant to partially address this need, the reality of small sample sizes and limited research time available to clinical investigators speaks to the need for a broader based research approach directed towards scientific verification of the suggested communication and care inclusion elements, and evaluation of their capacity to help families achieve human awareness and insight within the experience of critical illness. Data from the most salient confirmatory studies can serve as foundational to a wider multicenter approach. Given the magnitude and scope of testing communication elements within the relationship based family centered nursing approach, coupled with inclusion specifics found within the integrated palliative/critical care structure, a demonstration project with funding from NINR or Robert Wood Johnson is proposed as a strategy for obtaining data on the most effective approaches to achieving family member awareness and insight within the experience of a loved one’s critical illness.
Nursing Practice

It has been noted that nursing practice involves various elements, including understanding conceptualizations of care (Willis & Grace, 2011). Implied in this is the need to apply validated findings to address human health needs. While not yet validated, representing an additional area of future researcher, Brenna’s narrative informatively highlights her actualization of a conceptualized sequential process to achieve family member bedside presence and enhanced family member understanding of their loved one’s situation. The steps she outlined are noted to include the initiation of a trusting nurse/family relationship through encouraging family member bedside presence, achieving additional goals of enhancing family comfort with the foreign environment and creating opportunities for family/nurse dialogue. Next, small amounts of information are provided while simultaneously assessing the family’s ability to both assimilate and expand upon the information. Family member anxiety is assessed on an ongoing basis, with reductions often promoted through information sharing. Notably, these interventions appear aligned with Morse and Penrod’s (1999) suggested model of conceptual integration among enduring, uncertainty, suffering and hope, and offer an opportunity for further research. Additionally, normalization of the environment is used as another strategy to reduce uncertainty and anxiety. Approaches such as the one described here assure the integrity of the patient/family relationship by supporting the family’s unique way of being and supplementing it through presence and sharing. This type of critical care nursing practice is transformative when employed within the ICU environment.

An additional practice component includes the development of nursing practice strategies necessary to effectively care for inextricably linked patients and their families, and the need to develop tools by which the additional workload can be captured. While the value of family
member inclusion in care has been notably articulated through this study’s results, it is recognized that doing so involves the need to expand nursing practice from the critically ill patient to both patient and family members. No distinct guidelines or effective strategies for accomplishing or measuring this goal have been developed. This absence is particularly notable among those who are initiating their critical care nursing practice. The intensity of family communication and inclusion needs coupled with the challenges of learning a new practice specialty can be burdensome for junior staff members, many of whom are surprised to find the family inclusion and communication work to be more difficult than gaining expertise within the subspecialty practice arena. While these nurses ultimately find family involvement both enjoyable and professionally satisfying, ways of mentoring junior staff during the first year of practice need to be explored.

_Nursing Education_

Understanding how to care for critically ill patients is achieved through structured academics at the undergraduate level and supplemented by unit based formal and informal teaching. However, this model may fail to provide content aimed at enhancing the learner’s process of mutual engagement between the nurse, patient and family. Failure to include this information leaves engagement to chance, excluding an essential nursing practice element.

Results from this study begin to unfold distinct elements within the mutual engagement processes among critical care nurses, their patients and loved ones. These elements, including relationship based care, patient centered care, family centeredness, palliative care and critical care are all expanded upon within the academic literature, and can be included within the nursing curriculum. The key suggestion emanating from this study is that they be considered within the umbrella of the unitary-transformative paradigm. Doing so will frame them from a perspective of interconnectedness, assuring that they are taught as an integrated whole rather than as segregated
entities. Further, this may be accomplished through the use of simulation, a modern approach to teaching that mimics the care environment and includes the opportunity for debriefing, which serves as a learning mode through critique of actual practice.

_Health Policy_

While family members of critically ill patients were previously considered “visitors” in the ICU, they now are distinctly recognized as family members. Salient within this recognition is the shift from considering the intensive care unit as within the ownership of the care team and, in particular, of nursing, to reframing it as a shared space housing care providers, patients and their loved ones. Further, it is recognized that the critical care experience not only impacts patients but extends to family members, potentially causing a degree of emotional distress that can evolve to measurable forms of psychiatric illness. It is newly appreciated that our care of patients’ families directly and longitudinally impacts their mental health and emotional wellbeing. Our focused attention must be at preventing deleterious emotional wellbeing among both patients and their loved ones.

As demonstrated in this study, and in addition to its scientific and physiologically based interventions, expert nursing care is composed of a nurse/family relationship that facilitates human growth through practice which is embedded in a palliative/critical care environment. Newman considers the nursing relationship to be asymmetric when it promotes human growth and transcendence through consideration of additional information and its subsequent insight, causing consciousness expansion (2008). Within this study, there is evidence supporting the value of family presence as a mechanism to introduce families to the minute to minute realities of their loved one’s precarious clinical status and, by doing so, exposing loved ones’ to life’s uncertainty, or life disorder, creating the opportunity for purposeful activity. Nursing is coupled with the family
at the bedside through a caring, asymmetrical relationship, introducing information as requested by
the family and as deemed necessary by the nurse and care team. Together, the experience of
presence in concert with the caring nurse creates opportunities for purposeful growth and personal
unfolding to higher levels of consciousness, or health, through recognition of the current disease as
a manifestation of their loved one’s unique pattern.

Publication of this work and future confirmatory studies will highlight this model’s important
role in supporting and enhancing the emotional health of our family members. This type of
transformative critical care nursing practice will enhance the health of society, and should be
considered as an important public health initiative throughout the critical care community. It is
possible that nursing’s application of this elegant care approach which facilitates human wellbeing
through the exploration of meaning will have a pronounced impact on the health of our critically ill
family members.

Empiric Expansion of Existing Literature

Critical care end of life practices have yet to be fully implemented and advanced to their fullest
capacity. Literature addressing necessary practice enhancements has been synopsized by Azoulay
and Siegel (2011) to include a) alignment of care with patient preferences and values (Singer &
Lowy, 1992; The SUPPORT Principal Investigators, 1995); b) continued clinician involvement in
dying patients’ care to assure symptom management (Lynn et al, 1997), promotion of respect and
dignity, and provision of support to loved ones (Emanuel, 1998; Faber-Langendoen & Lanken,
2000; McDonagh et al, 2004; Quill, 2000); c) implementation of family centered care and support
for effective family functioning during decision making through the provision of compassionate
and clear communication (Azoulay & Siegel, 2011); 4) a philosophy of clinician/family
communication that encourages family expressions of emotions, concerns and questions (Keenan,
Mawdsley, Plotkin, Webster & Priestap, 2000) and 5) implementation of ethically sound decision making processes which respect known patient wishes and, consequently, help prevent families from experiencing the burden of complicated grief (Azoulay et al, 2005; Cuthbertson & Margetts, 2000; Siegel, Hayes, Vanderwerker, Loseth & Prigerson, 2008). Additionally, U. S. ethical and legal perspectives aligned with a national societal consensus during in the 1980s to recommend the inclusion of patient prognosis, patient and family values, clinician judgments, mutually agreed upon goals of care and palliative support during the dying process in life sustaining treatment decisions (Solomon, 2003). While these approaches may not appear applicable to all critically ill patients given the overall 80% survival rate, deeper exploration acknowledges these themes as extremely similar to those contextual elements within the MICU’s family meeting structure, where prognosis, clinical findings, patient and family values and decisions to proceed or forgo life sustaining treatments are all addressed.

Two major quantitative ICU end of life studies have failed to demonstrate significant findings. Investigators within the large, multicenter SUPPORT trail designed an intervention to enhance physician awareness of resuscitation preferences and improve end of life care quality (The SUPPORT Principal Investigators, 1995). More recently, Curtis and colleagues (2011) employed cluster randomization among 12 hospitals to introduce quality improvements including clinician education, support for local champions, clinician feedback and system support including posters, pamphlets and standardized life support withdrawal order forms. In her critique of SUPPORT, Solomon (2003) pointedly appreciated the study’s failure to link conceptual premises and research methods by, for instance, reducing understanding of end of life decision making to measurable components of information and values, and how doing so fails to effectively examine the impact of the lived experience of suffering has on outcomes. Similarly, in an editorial review of Curtis’
study, Azoulay and Siegel (2011) appreciated the investigator’s focus on hospitals and clinicians but acknowledged the absence of patient and family inclusion.

This dissertation illuminates opportunities for a comprehensive research agenda including the addition of a unitary-transformative paradigmatic approach to future studies exploring the critical illness experience among loves ones. Doing so will effectively associate the appropriate conceptual focus of an unbroken person/environmental whole with the praxis methodology which, as has been demonstrated here, so effectively reveals the depth of family member and registered nurse bedside experiences. Studies employing an exclusively quantitative approach, such as those noted above, have failed to extrapolate the human experience, such as the encouragement a family member experienced by watching their loved one’s facial expressions, the expertise with which the registered nurses harmoniously integrate critical and palliative care, and the engagement among family members and clinicians. The recommendation for a mixed methods approach to subsequent empiric exploration of family member experiences supports Newman’s (2008) contention that care is optimized when analytical and narrative thinking are combined.

Limitations

This study has several limitations. Family member participants were self selected. Registered nurses were also self selected in response to an email inviting participation sent to them by the unit’s Nursing Director. Accordingly, participants may have had more of a desire to engage in an exploratory reflective process or, in the case of registered nurse participants, may have perceived a closer relationship with the participant/researcher, who also serves as the unit’s Clinical Nurse Specialist. As a result of the self selection process, the perspectives of those with less of a desire to discuss meaningful experiences with their critically ill family member were not captured, and may
reflect alternate perspectives. In addition, the small number of participants and limited diversity of age, ethnic and socioculturalism also limits study results.

The study was also limited by its design. Data acquisition occurred at one point in time within the critical care experience. It is possible that alternate perspectives may have emerged if the study had progressed throughout the course of the critical illness.

Study results were also impacted by the author’s limited experience as a researcher. It is possible that a larger number of participants could have been recruited if the author was more seasoned. Further, more advanced understanding of the praxis methodology within HEC could have produced richer or more detailed findings.

Conclusion

This study examined the experiences of family members with critically ill loved ones, and the experiences of registered nurses providing their loved one’s care. Experiences of meaning were examined employing Margaret Newman’s theory of Health as Expanding Consciousness and its associated praxis method of data analysis. The study demonstrated the importance of relationship based patient and family centered nursing care provided in an integrated palliative critical care unit. Further, the themes which emerged from family member and registered nurse participants offered new understanding of family members’ experience of critical illness and critical care nursing practice. In particular, the impact of expanded consciousness on ensuring implementation of prior goals of care decisions, and the value of an integrated palliative care environment on establishing meaningful nursing care was appreciated. These unique findings offer important implications for nursing theory, research, practice, education and health policy. Concomitantly, they suggest the impact of an asymmetrical nursing relationship on enhancing family member health through insight and transformation gleaned via dialogue between family members who are
present at their loved one’s bedside and the critical care nurses providing care integrated by elements of both critical and palliative care. Finally, this work adds to the body of literature supporting findings of and emanating research data from Margaret Newman’s theory of Health as Expanding Consciousness.
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### Family Member Demographics

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<tr>
<td>Age, years, mean (range)</td>
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<td>Female, n (%)</td>
<td>7 (87.5 %)</td>
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<tr>
<td>Race/ethnicity n, (%)</td>
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<tr>
<td>White</td>
<td>7 (87.5%)</td>
</tr>
<tr>
<td>Black</td>
<td>1 (12.5%)</td>
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<tr>
<td>Hispanic</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Other</td>
<td>0 (0%)</td>
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<td>Religion, n (%)</td>
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<tr>
<td>Catholic</td>
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</tr>
<tr>
<td>Protestant</td>
<td>2 (25%)</td>
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<tr>
<td>Jewish</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>2 (25%)</td>
</tr>
<tr>
<td>Marital Status, n (%)</td>
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<tr>
<td>Married</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>Divorced/Separated</td>
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<tr>
<td>Widowed</td>
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<tr>
<td>Never Married</td>
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</tr>
<tr>
<td>Patient ICU LOS, median (range)</td>
<td>12.3 (6-25)</td>
</tr>
<tr>
<td>Family relationship to patient n (%)</td>
<td></td>
</tr>
<tr>
<td>------------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Spouse</td>
<td>4 (50%)</td>
</tr>
<tr>
<td>Adult child</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td>Other family</td>
<td>2 (25%)</td>
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<tr>
<td>Meaningful person</td>
<td>1 (12.5%)</td>
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<table>
<thead>
<tr>
<th>Number of family visits to ICU, n (%)</th>
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<tbody>
<tr>
<td>One</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>2-5</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>&gt; 5</td>
<td>8 (100%)</td>
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<tr>
<th>Education, n (%)</th>
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<tr>
<td>Some high school</td>
<td>0 (0%)</td>
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<tr>
<td>High school graduate</td>
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<tr>
<td>Some college</td>
<td>3 (37.5%)</td>
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<tr>
<td>College graduate</td>
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<tbody>
<tr>
<td>Full time</td>
<td>4 (50%)</td>
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<tr>
<td>Part time</td>
<td>2 (25%)</td>
</tr>
<tr>
<td>Retired</td>
<td>1 (12.5%)</td>
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<tr>
<td>Not currently employed</td>
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<th>Income, n (%)</th>
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<tbody>
<tr>
<td>&lt;$25,000</td>
<td>1 (12.5%)</td>
</tr>
<tr>
<td>$25,000-$50,000</td>
<td>5 (62.5%)</td>
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<tr>
<td>$&gt;50,000</td>
<td>1 (12.5%)</td>
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<tr>
<td>Rather not report</td>
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</table>
Appendix B

*Research Study Fact Sheet for Family Members*

Study Name: An exploration of meaning among ICU families and nurses employing Margaret Newman’s Theory of Health as Expanding Consciousness

This research study is being conducted to understand your personal experience of having a loved one in an intensive care unit. Knowledge gained from this study may help us to understand the links between you, your loved one and critical care nursing.

This study is being conducted in the Medical Intensive Care. If you agree to participate in the study, you will be asked to talk with the investigator for approximately 60 to 90 minutes. You may be asked to participate in a follow up session lasting approximately 45 to 60 minutes, where the investigator will share her analysis with you both in writing and in graphic form. The sessions will be tape recorded and take place in a private hospital space. No identifying information will be included. The only known discomfort to study participation is the potential for becoming emotionally upset when talking about your experience. A mental health professional will be made available to you at no cost should you experience disturbing emotional feelings.

There are no known benefits but the knowledge gained from this study may help other families/significant others of critically ill patients.

Participation in this study is completely voluntary, and you may withdraw from the study at any time you wish. If you decide to discontinue you participation in this study, you will be treated in the usual and customary fashion as a family member.
All study data will be kept confidential and you will not be identified. However, if you do seek assistance for emotional upset from a hospital mental health professional, your study participation would no longer be confidential.

Concerns or questions about this study may be directed to the study’s principal investigator, Lillian Ananian, RN, a doctoral candidate at Boston College School of Nursing, and/or The Partners Human Research Committee at any time. Contact information for both is included at the end of this form.

The principal investigator’s signature below indicates that verbal consent has been obtained.

Lillian Ananian, RN_____________________________ Date________________

Contact Information:

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116 Huntington Avenue, Suite 1002  
Boston, MA. 02116  
Tel: (617) 424-4100  
Fax: (617) 424-4199
Appendix C

*Staff Nurse Demographics*

<table>
<thead>
<tr>
<th>Age, n (%)</th>
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</thead>
<tbody>
<tr>
<td>20-29</td>
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<tr>
<td>30-39</td>
</tr>
<tr>
<td>40-49</td>
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<tr>
<td>50-59</td>
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<tr>
<td>&gt;60</td>
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</table>

<table>
<thead>
<tr>
<th>Gender, n (%)</th>
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</thead>
<tbody>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Total number of years as RN, n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-5</td>
</tr>
<tr>
<td>6-10</td>
</tr>
<tr>
<td>11-15</td>
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<tr>
<td>16-20</td>
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<tr>
<td>&gt;20</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Total number of years as MICU RN, n (%)</th>
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<tbody>
<tr>
<td>0-5</td>
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<td>6-10</td>
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<tr>
<td>11-15</td>
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<tr>
<td>16-20</td>
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<tr>
<td>&gt;20</td>
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<tr>
<td>Highest nursing degree obtained, n (%)</td>
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<td>--------------------------------------</td>
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<tr>
<td>Diploma</td>
</tr>
<tr>
<td>AD</td>
</tr>
<tr>
<td>BSN</td>
</tr>
<tr>
<td>MSN</td>
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</tbody>
</table>
Appendix D

Staff Nurse Research Study Fact Sheet

Study Name: An exploration of meaning among ICU families and nurses employing Margaret Newman’s Theory of Health as Expanding Consciousness

This research study is being conducted to evaluate personal meaning during a family member’s critical illness. Further, it aims to explore experiences revealed by clinical nurses when providing care for a family’s loved one. Knowledge gained from this study may help to further elucidate the interface between critical care nurses and families.

This study is being conducted in the Medical Intensive Care Unit (MICU) to fulfill requirements of the principal investigator’s doctoral dissertation. If you agree to participate in the study, you will be interviewed for approximately 60 to 90 minutes. You will also be asked to participate in a follow up session lasting approximately 45 to 60 minutes, where results from the interview will be shared with you both in writing and in graphic form. The interview will be tape recorded and take place in a private hospital space. No identifying information will be included when the interview is transcribed. The only known risk to study participation is the potential for emotional upset when talking about family and/or significant others. A mental health professional will be made available to you at no cost should you experience disturbing emotional feelings.

Study participation is limited to MICU staff nurses who are employed on a full or part time basis and have completed at least 6 months of MICU practice.

Participation in this study is completely voluntary, and you may withdraw from the study at any time. If you decide to discontinue you participation in this study, you will be treated in the usual and customary fashion.
All study data will be kept confidential. However, if you do seek assistance for emotional upset from a hospital mental health professional, your study participation would no longer be confidential. Information from this study may be used in publications and presentations, but participant identity will remain confidential.

Concerns or questions about this study may be directed to the study’s principal investigator, Lillian Ananian, RN, a doctoral candidate at Boston College School of Nursing, and/or The Partners Human Research Committee at any time. Contact information for both is included at the end of this form.

The principal investigator’s signature below indicates that verbal consent has been obtained.

Lillian Ananian, RN ____________________________ Date ____________________

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Appendix E

Participant Groups Three through Seven

Participant Group Three

Patient Information: The patient was an older man with end stage alcoholic and nonalcoholic liver disease who required MICU admission for hypotension, acute kidney injury and an elevated serum lactate. The patient was transferred to the general care unit following his initial MICU admission, but required a MICU readmission, from which he succumbed. The interviews were obtained during his initial admission. Participants include his wife Evelyn and MICU RN Grace.

Evelyn’s Narrative Summary

Evelyn described parental gifts generously offered to her by her mom and dad. Compassion and caring were acquired from her mom, while her dad taught her to be reasonable. Evelyn observed these first hand, particularly as her mom lovingly cared for her dad during his multiple hospitalizations for cancer, from which he ultimately died. Her mom also taught her the value of living a life free of regrets, and the importance of always doing what is right as a path towards this goal. Evelyn’s devotion to her husband, being present at his bedside, attending to his needs, remaining strong in his presence but allowing herself to “fall apart in private”, all reflect her application of the important life lessons bestowed on her by her parents.

Evelyn experienced a severe, year long depression following the death of her father. She met Frank at the end of this difficult period, feeling truly amazed by the relationship’s positive impact on her emotional health. She described this as “everything just kind of became good again”. Her life transitioned from grief to joy as she engaged in the beauty of a relationship grounded by values of mutual support, acceptance and team work. Frank and Evelyn married eighteen months after they first met.
Their life as a married couple experienced its first significant challenge when Frank’s son Cal’s substance abuse issues came to light, placing Evelyn in a new found relationship with Frank’s former wife. Cal emerged successfully from his addictions to both heroin and alcohol, and has remained drug free for the past eight years. Evelyn credited their collective focus on Cal while dismissing any tension between current wife/former wife roles as the two most salient contributions to both Cal’s successful addiction management and the relationship which evolved between Evelyn and Frank’s former wife. As stated by Evelyn “…we concentrated on Cal; we did the right thing”. Evelyn further illuminated how she applies the life lesson of “doing the right thing” to achieve a healthy relationship between herself, Frank, and Frank’s former wife.

And in a way I’m glad I have a relationship with her, where I can call her in an emergency and she’ll be there but in another way she always finds a way to cross a line of her, she doesn’t know her boundaries, so we need to reset (the boundaries). But, with me taking the higher road with her, it helps Frank and I because we don’t fight about her and there is no bickering about her. We both know who she is, what she is, why she is, and we just accept her as that, and we don’t dwell on it.

And, finally, she offered insight on the impact Cal’s addictions had on their marriage.

Well, I went through a lot with Cal, and that was pretty early in our relationship and I think that proved to him (Frank) that I would be there through thick and thin. I think that kind of helped solidify our relationship you know, going through all of that because it is horrible, you know, not knowing where your son is, you know. We’ve been through a lot with Cal and he has turned into a remarkable young man really.

Evelyn’s caring and compassion were not only evident during this hospitalization, but were revealed as she assisted Frank’s recovery from prostate cancer surgery seven years ago. She described a stalled recovery due to a post operative infection, and its consequent strengthening of their marital bond. Recognizing that he would require additional care following hospital discharge, she equipped herself to provide Frank’s care in the comfort of their home by tapping into knowledgeable registered nurses, including both personal friends and hospital staff. Evelyn reflected on the experience by commenting “…and that was pretty amazing, to be able to nurse
him like that, and to do the things for him that needed to be done, you know, it was nice, it was nice.”

While Cal’s addictions and Frank’s prostate cancer solidified and strengthened their marital bond, their relationship was jeopardized by Frank’s new diagnosis of liver disease, thought to be the combined result of alcohol ingestion and use of a lipid lowering medication. Although Frank achieved sobriety in the past year, he did so by breaking off relationships among friends with whom he formerly drank, causing him to feel disinterested in life and sinking him into depression. Evelyn believed the situation was so severe that it required an ultimatum, and told Frank “you either change your attitude or you move out because I am not going to watch you start drinking and kill yourself”. Evelyn’s approach helped Frank achieve a renewed interest in life. Frank sought emotional help, and began pharmacologic treatment for his depression. Evelyn described their last six months together as “….beautiful….we’ve done things we’ve never done before and we are loving life a different way and it is wonderful.”

Frank’s decision to forgo liver transplant in the face of life threatening hepatic failure further solidified their marital bond. Frank believed the risk of experiencing debilitation following transplant to be too great, deciding he would rather “…just hold, go out early”. Evelyn employed the compassion and caring learned from her mom to assist Frank with his needs, as she dealt emotionally with the reality of Frank’s limited life expectancy. Evelyn hoped for another three to five years of life for Frank, realizing she was unsure if that was a realistic time frame, but acknowledging the pain of hoping for any additional time beyond the three to five year mark. She described her commitment to Frank’s decision.

It is…what he wants I can’t…we’re a team you know…we are never divided on our thinking, and I have to think that way, I have to support him. I’m not going to fight with him, and have him go through that intense situation of life (transplant), without 100% chance of a good outcome. I’m not going to put him through it; he’ll hate me
Evelyn also described some of Frank’s endearing characteristics, and her hope for his return home.

He’s great, I wish you…I wish people could know him here without being sick you know, because he is an incredible person. He is smart, he is so smart, he is so patient, he is so forgiving, kind, loving. He is romantic, he leaves me these little notes, these silly little notes, I’ll find them everywhere. He is not perfect. He is such a procrastinator I could kill him (laughter). You know I said to his son today, I said, all those imperfections, his sloppiness, I call it his laziness but he is really just a procrastinator, you know, I’ll take it all, I’ll take it all just to have him home.

We also discussed Evelyn’s potential for depression as she faces Frank’s death.

I’m gearing up for it…I said to my mother just this morning before I came in I said to my mother that I don’t want…I know my grief is going to be huge but I really don’t want to go through that grieving process again…because it is so hard to do. I know it has to be done, I know it is the natural process but I, I don’t know, I don’t want it to be as severe as it was before.
## Participant Group Three
**Evelyn (Wife)**

<table>
<thead>
<tr>
<th>Father’s Death</th>
<th>Met Patient</th>
<th>Patient’s Son’s Addiction</th>
<th>Patient’s Prostate Cancer</th>
<th>Liver Disease Diagnosis</th>
<th>Current Critical Illness</th>
</tr>
</thead>
</table>
| Deep year long depression | Met patient as depression resolved | Married 1.5 years after meeting | Gifts of the relationship:  
- mutual acceptance  
- alignment as a team | Helped to further solidify their relationship  
Revealed wife’s devotion to patient  
Established relationship with patient’s ex-wife | Achieved interpersonal gifts by assisting patient with his recovery | Struggle with sobriety led to depression  
Crisis point in marriage  
Accepted medical treatment for depression  
- life changing  
- life style changes led to wonderful past 6 months | Reflection on parental gifts  
Mom: compassion  
Dad: reason  
Realizing patient’s life will be short  
Hoping grief will be less powerful than with father’s death  
Acceptance of patient’s decision to forgo transplant |
Evelyn’s Response to the Pattern Analysis

The transmuted diagram of Evelyn’s narrative beginning with the parental gifts bestowed upon her and culminating with this current critical illness was shared with Evelyn during the second interview, providing her the opportunity for reflection and clarification. Evelyn validated the timeline, and indicated that the events were accurately portrayed. She described the document as one which she would cherish for a lifetime, but did not offer any additional insights.

Evelyn’s Pattern Analysis Summary

Narrative analysis demonstrates clear and distinct alignment between Evelyn’s life experiences and her interpersonal growth. Evelyn’s life experience of severe depression concluded as she and Frank began a relationship balanced by acceptance, interpersonal support and emotional health.

So, and we have a very good marriage, we don’t try to change each other, we accept each other for who we are. And we say a couple of things…I’ve never been married before, but Frank was, we met when we were older, and that helped a lot because we understand life…you understand life better you know, so. Ummm. He is incredible; he is supportive of any endeavor. Even if he doesn’t agree with something he will just preference it with well, ‘I don’t know if I would do that, but, if I did’…and then I know that he doesn’t agree, you know, but he’ll never say no, he never says no. And I never say no to him when he is doing something. I will say ‘ I don’t really agree with that, but, since you are doing it, this is my…’ so we go from there. We just accept each other, who we are, we never go to bed angry, we’ll talk it out.

Cal’s addiction and its subsequent impact on Evelyn’s relationship with Frank’s former wife challenged their marriage in its early stages, but ongoing use of acceptance and healthy emotional dialogue again fostered successful outcomes. Evelyn and Frank’s former wife are engaged in an acceptable relationship, and Cal has developed into a “remarkable” young man who has returned to school to pursue a college degree.

Evelyn’s consciousness evolved to stage four, as described by Young’s trajectory, following Frank’s sobriety and its accompanying depression, an event that fostered a turning point in their relationship. Evelyn realized the need for choice to be made to prevent Frank from returning to
alcohol as a treatment for his depression, and facilitated this by presenting an either/or option for Frank. The couple’s new and beautiful life following Frank’s decision to seek mental health treatment is clearly evident in Evelyn’s words: “it’s been life changing and all for the better. It really has, it really has”. The pattern expression of the whole is represented by the theme “Lovingly Applying Life’s Gifts and Husband/Wife Synergy to Pre-established Goals of Care”.

*Grace’s Narrative Summary*

Grace admitted Frank to the MICU in transfer from the general care unit. She facilitated and participated in the initial family meeting with the patient and his wife and, because he was awake, she assured Frank’s participation by holding the meeting at his bedside. Her presence and participation provided Grace an opportunity to learn more about them as both individuals and as a couple facing a critical illness, and to understand their initial care decisions. She supported their desire to start with an aggressive treatment plan, given the new onset of Frank’s critical illness and the current uncertainty of both its etiology and potential for recovery.

Facilitation of family meetings is a well established component of Grace’s nursing practice. She encourages early meetings in which she comfortably serves as facilitator, participant and active listener, following which she compassionately implements decisions emerging from the family meeting process. Yet, she found herself experiencing a deeper level of emotional involvement following Frank and Evelyn’s meeting; a connection she felt was fostered by observing their obvious love for each other. She described it as “…their love for each other…just even the way…the way that he would like look at her, and she would look at him”.

Unlike most patients, Frank was awake and lucid throughout his MICU stay, providing him the opportunity to actively participate in his care and decision making, and offering Grace the opportunity to experience and understand Frank and Evelyn first hand. Grace described this as
unusual, but ultimately positive, as it helped her to develop a deeper appreciation of the couple than commonly occurs in her practice. She contrasted it to her more frequent experience of knowing patients through the eyes of patients’ families and acquaintances which, as a result of her experience with Frank and Evelyn, she realized was “one sided”.

Frank and Evelyn’s love for each other was “palpable” according to Grace. As she witnessed the intensity of their love, she developed an appreciation of its effects, both on her personally and her practice. She was inspired to engage in a more meaningful nurse/patient/family relationship in which she provided her very best nursing practice, but she also recognized a greater sense of personal sadness, particularly as the severity of Frank’s hepatorenal failure began to unfold. Ultimately, it led her to clearly understand and appreciate Evelyn’s desire to provide Frank whatever was best, even if it meant taking him home to die. Grace offered a description of her impressions:

I think that just the way that I could see their love for each other, I just felt like I wanted to do what was best for him and was best for her…I really wanted to like help her through everything and him, cause he was completely awake, which I think is also different from what we usually deal with because we usually have all intubated and sedated…we don’t usually see that dynamic…it is usually one sided. But um, I don’t know, I just felt like I really connected with them in that way.

The rapidly evolving diagnosis of hepatorenal failure and Frank’s associated clinical decline forced Evelyn and Frank to frequently re-evaluate goals of care and life sustaining treatment decisions. Grace remained solidly connected with them during this period, recognizing that their dynamic and ever changing needs necessitated a fluid approach to her nursing care.

…it seemed like he was doing OK that first day, and then it just evolved so quickly that it was just kind of a fast, like, I don’t even know how to describe it. She needed different things throughout, in terms of support, so I was just trying…I don’t even know how I knew what she needed….I was just trying to let her know that I was there for her and for him.
Grace guided and supported Evelyn through this dynamic period, encouraging her to consider differences between decisions based on possibilities versus those made in the face of actualities.

…when we first had that initial discussion that first day when he was actually pretty stable, he actually said that he wanted to be DNR, and she (Evelyn) said that off the bat, too. She said we have talked about this many times; he wouldn’t want anything extraordinary done, so we should just make him DNR. And so, at that point we made him DNR, and that following night is when he actually went into the V Tach (ventricular tachycardia) … and then they (the physicians) had called her… and then so then she changed the code status, so there were actually a lot of things evolving. And then I know she felt bad… so she felt bad about that (changing the code status). But even me and the team (medical team) were like things always change, constantly; there is no need to be feeling bad. And it is hard to be having a conversation about something that is potential rather than actual.
<table>
<thead>
<tr>
<th>Initial care experience</th>
<th>Grace's experience of caring for an awake patient</th>
<th>Grace's experience of a loving couple</th>
<th>Grace's experience of the unfolding critical illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initial early connection at admission</td>
<td>Unique connection with patient</td>
<td>Bearing witness to a loving husband/wife couple experiencing profound illness</td>
<td>New onset hepatorenal failure recognized; patient's clinical decline appreciated</td>
</tr>
<tr>
<td>Facilitated early patient and family bedside meeting</td>
<td>Fostered understanding in a deeper way than usual</td>
<td>Their love was palpable, which caused Grace to experience a greater sense of meaning in her relationship with the patient and his wife, but also caused her to feel sad about the impact this illness was having on their relationship.</td>
<td>Patient rejected ongoing clinical interventions</td>
</tr>
<tr>
<td>Provided ongoing care throughout initial admission</td>
<td>Patient was illuminated first hand, rather than through others</td>
<td>Grace was inspired to offer her very best to them both</td>
<td>Patient established the goal of returning home</td>
</tr>
<tr>
<td>Appreciated patient/family desire to be aggressive, given new onset illness</td>
<td>Felt enhanced connection through knowing them first hand rather than via the Get to Know Me Poster and/or through eyes of family</td>
<td>Appreciated wife's sincere desire to do whatever her husband wanted, even if it meant taking him home to die</td>
<td>Supported wife during turbulent LST and GCS decisions, reinforcing dynamic nature of the critical care experience and differences between possibilities (pre hospitalization) and actualities</td>
</tr>
<tr>
<td>Sensed a difference with this family; felt much more connected following the initial family meeting</td>
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</table>

Grace (RN)

Grace → Patient

Patient/wife dyad

Patient

Wife

Grace → Patient

Patient/wife dyad

Wife

Grace → Patient

Wife
Grace’s Response to the Pattern Analysis

The emergence of distinct experiences during Grace’s care for Frank and Evelyn, including Grace’s initial connection with them as individuals and as a couple, caring for a conscious, lucid patient and one in whom the loving spousal relationship was palpable, and her care provisions in the wake of worsening illness were shared with Grace, providing the opportunity for reflection and clarification. She agreed with the categorizations and descriptions, but did not offer any further realizations resulting from this reflective opportunity.

Grace’s Pattern Analysis Summary

Grace’s pattern analysis, based on the narrative account of her practice and its diagrammatic representation, displayed an emerging pattern of synergistic connections with patients and families, which was greatly enhanced by her experiences caring for Frank and Evelyn. Grace witnessed and appreciated the value of knowing this patient and his wife first hand, far beyond that which the “Get to Know Me” poster or family descriptions could provide. Further, the palpable nature of the couple’s love and devotion fostered emotional connections between them as a triad of nurse, patient and wife. Although she felt a greater sense of sadness than she had experienced with other patients, she remained connected to her emotions, allowing both emotions and her patient/family understanding to intuitively guide her care. Ultimately, she employed this understanding to help Evelyn feel comfortable with her decision making process as she changed Frank’s goals of care to include defibrillation in the setting of ventricular tachycardia. Grace’s consciousness evolved to stage four, as described by Young’s trajectory, as she acknowledged advancement from compassionately implementing family wishes to employing emotional connections as the contextual foundation for a more synergistically connected practice. The pattern expression of the
whole is represented by the theme: “Direct Understanding of Patient/Family Emotional Bonds as Inspiration for Developing a More Synergistically Situated Nurse/Patient/Family Relationship.”

**Participant Group Four**

Patient Information: The patient was an older man with shock due to sepsis. A component of his past medical history included prior episodes of Lyme related illnesses and a traumatic right arm amputation. The patient ultimately improved and was transferred out of the MICU.

Participants: patient’s wife Helena and MICU RN Irene

**Helena’s Narrative Summary**

Helena and Mr. Jones’ 57 years of marriage began shortly after they met while leading a church youth group. Helena was teaching music in a New York State public school system, and Mr. Jones was returning to college. Their honeymoon brought them back to Helena’s native state of New Hampshire and a visit to the White Mountains, where her husband fell in love with hiking.

Three years later, following the birth of their son, Mr. Jones’ transferred to a college located closer to his parents’ home. This move provided the couple an opportunity to live with Mr. Jones’s parents for the next two years. Helena spoke of her loving relationship with her mother-in law, including similarities in their child rearing values.

A love for New England coupled with the completion of Mr. Jones’ undergraduate degree inspired the couple’s return to New Hampshire. Helena gave birth to their daughter, and Mr. Jones returned to graduate school. Helena remained active in music, moving from public teaching to providing private piano lessons.

Mr. Jones accepted a temporary teaching position in a private New Hampshire school system. The lack of a permanent position led to a job search and acceptance of a full time teaching position in a private Ohio school. They moved into an Ohio community styled in New England fashion by
its Connecticut settlers, spending the next 17 years raising their two children while actively participating in Cub Scouts, scout mothers, and the Explorer post. Helena spoke with admiration as she talked about her husband’s successful leadership of the Explorer Troops’ summer camping and hiking trips.

Helena described the circumstances surrounding her husband’s arm amputation. He was helping his uncle milk cows when a fierce storm occurred, damaging the barn in which they were working, pinning him under a heavy door. His arm had to be amputated due to rapidly advancing gas gangrene. Mr. Jones was cared for by his two sisters, both of whom were nurses. During his recovery, which was miraculous given the very small chance of survival, he posed two questions to his sister: 1) did they take my arm off? 2) can I row a boat again? She responded “yes” to the first question and “if you want to” to the second. Helena described this interaction as the only therapy he ever needed. He has kept those words with him all his life, remaining active in numerous endeavors. Helena spoke of her admiration for the courage with which he has lived his life.

The couple’s complimentary personalities, personal growth experiences and life changes have afforded them the opportunity to continually learn new things about each other. Their numerous camping trips, considered by Helena as the most significant element of their married life, reflect their mutual love of geography and history. She noted the synergy between their trips and this critical illness:

…and several trips that have included Yellowstone; we’ve done most of the big national parks and some of the smaller ones. As he was here in intensive care, we had the television set to the meditation channel, and many times it would show pictures of the places we have been, and I was able to get him to be roused; he was so sedated he couldn’t open his eyes enough but I would tell him look, they are showing Yellowstone where we went on our trip and even though he was intubated he was able to nod his head and respond…And frankly sitting there watching those pictures was probably better for me than it was even for him. It was relaxing for me, and quieted me down…when I look back upon my experiences here in the ICU, I will probably remember that part the most.
Mr. Jones opened a tax business after retiring from his teaching career. Helena transitioned from teaching music to a school counselor role and then, in retirement, became a master gardener. Helena used the analogy of overlapping circles to describe their marriage. The circles overlap greatly during their trips together, but less so when in opposite ends of the house. Helena acknowledged her husband’s support of all her endeavors irrespective of how encapsulated they were or were not within the spectrum of their overlapping circles.

Helena and her siblings were raised by a mother whose parenting style focused on developing each child’s individuality. Helena and Mr. Jones’ agreed on this same philosophic approach to parenting, and believe that their children’s independence and responsibility are testaments to their success. The children’s presence during their dad’s critical illness was, to Helena, a clear demonstration of their individuality and responsibility. Mr. Jones acknowledged the tremendous support he felt from his family’s presence, and Helena noted the support provided by church and gardening club members.

Mr. Jones and his wife organized a family meeting two years ago during a family visit to Fort Collins Colorado. They provided various documents, including a living will, financial information and emergency response plans. The emergency contact plan, implemented during this illness, worked well among immediate family, but issues were encountered with extended family member notification. Accordingly, they plan to organize a family debriefing to develop a new plan for contacting extended family members.

Helena discussed the fine line between remaining clinically informed and becoming overwhelmed by medical information. For her and her family, the most important method of obtaining information was being present on rounds:

It is a gift and our relatives who are in the medical field think it is just
wonderful...They think it is terrific. And for us it has been comforting, but since all of us are interested in learning and, of course, we can’t keep up on all of the terms and, then later, for a doctor to come in (and explain in more detail). That has meant a great deal to us; it really has.

She also mentioned the event’s impact on their life moving forward:

And he, he is going to wonder if he should go out and work out doors, probably, since he has had three sessions of Lyme disease and then this, and they all came from the deer tick, and we are scrupulous about checking each other out (for ticks). I have had one session of Lyme disease, and it was caught early. He has had much more severe reactions and, of course, this one, we are told this one is found only in elderly males. Um, we are speculating about how he is going to feel about staying where we are. We have thought about the two of us making a move. I have been more ready to do that than he has. He can go out the back door and pick up a trail and run through three miles, just through the woods. It is through working with brush or working in the garden. The field mice actually carry them from the deer. So, we are going to let him bring up the issues, when he is ready.
Participant Group Four
Helena (Wife)

<table>
<thead>
<tr>
<th>Barn accident</th>
<th>Couple met through church activities</th>
<th>Son's Birth</th>
<th>Returned to New Hampshire Daughter's Birth</th>
<th>Moved to Ohio</th>
</tr>
</thead>
</table>

Arm amputation following barn accident
Sister's encouragement provided necessary inspiration for patient to live life fully following accident

Marriage
Maine honeymoon
Helena introduced husband to White mountains which he loved “this is alright”

Helena developed loving relationship with mother-in-law, with whom they lived
Helena and her mother in law had similar approaches to child rearing, which helped to connect them as individuals

Husband won National Merit Scholarship which supported acquisition of his college degree
Helena worked as public school music teacher
Helena transitioned to offering private piano lessons following daughter’s birth
Patient developed career as math teacher

Couple raised children according to values of
- independence
- responsibility

Patient ← Sister
Patient ←→ Wife
Wife ←→ Mother in law
Patient ←→ Wife
Patient/wife dyad ←→ Children
<table>
<thead>
<tr>
<th>Cub Scout Explorer Leadership</th>
<th>Returned to New Hampshire</th>
<th>Critical Illness</th>
</tr>
</thead>
</table>

Patient and wife’s love of travel actualized through summer trips with Explorer group
- Patient retired from teaching and established new career as accountant
- Wife developed new role as master Gardener
- Couple traveled throughout US

Patient’s critical illness
- Two episodes of intubation followed by a slow but effective recovery

TV meditation channel displayed photos of beloved travel locations enjoyed by the couple throughout their lives together
- Comforted wife
- Grounded husband

Wife described their life as a couple being most integrated during their travel experiences

Patient → Wife
Patient → Wife
Patient → Wife
- Cub Scout Explorer Group
- Travel
- Meditation TV Channel Photos
Helena’s Response to Pattern Analysis

The transmuted diagram of Helena’s narrative beginning when the couple met and concluding with her husband’s critical illness was discussed with Helena during the second interview, providing her the opportunity for reflection and clarification. Helena validated the timeline and its accuracy. The participant/researcher shared her perception of synergy between their numerous trips and the destinations displayed on the MICU meditation channel. These were not appreciated by Helena at first but then, following more discussion, she was able to see the connection. Additionally, Helena described a conversation she had with Mr. Jones’ sister (the nurse who answered the two questions he had at the time of his arm amputation) shortly before this interview, who shared life long feelings she had not previously expressed. She did not offer any additional insights.

Helena’s Pattern Analysis Summary

Helena’s pattern analysis displays consistent evidence of sustained growth and order, representing stage five of Young’s consciousness evolution trajectory. Her life narrative represents an ongoing transcendence from personhood to familial dedication and growth. Ego transcendence is evident in the couple’s creation of advanced care planning decisions and the sharing of these decisions with other family members. Their parenting structure resulted in the creation of children with similar levels of consciousness, representing the couple’s transfer of pattern to two unique individuals. The pattern expression of the whole is represented by the theme “A Lifetime of Marital Growth Synergistically Integrated through Critical Illness”.

Irene’s Narrative Summary

Irene cared for Mr. Jones during day one and two of his MICU admission. She recalled that he was critically ill with sepsis, describing him as “very, very sick”…spiking fevers and dropping his
blood pressure like crazy”. Her primary focus was on establishing hemodynamic stability in the face of profound hypotension due to septic shock through administration and titration of fluids, pressors, management of “numbers”, and continued hemodynamic support through his first plasmapheresis treatment. The report she received from the admitting MICU nurse introduced her to some of Mr. Jones’ personal aspects, including the circumstances surrounding his arm amputation, his participation in marathon running, and his prior diagnoses of tick borne Lyme disease. Irene learned that the patient was married, and that his wife was staying at a nearby hotel. She provided phone updates to the patient’s wife throughout the night, but did not meet her in person.

The patient’s hemodynamic management was complicated by ongoing hypotension despite triple pressors in the setting of a high central venous (CVP) pressure. Irene believed the patient needed additional fluid resuscitation to achieve his blood pressure goal despite the high CVP, because of both hypovolemia from his profound diaphoresis and low cardiac output from the high level of positive end expiratory pressure (PEEP). She was initially unable to convince the physicians to order additional fluids, as they thought his elevated CVP represented adequate fluid resuscitation but, through ongoing clinical advocacy, she improved Mr. J’s hemodynamic stability using additional volume administration. Irene noted her impression that the impact of high PEEP levels on cardiac output is an important but often clinically underappreciated aspect of hemodynamic management.

Mr. Jones was heavily sedated with an opioid/sedative combination to achieve ventilator synchrony. He was repositioned frequently throughout the shift, both as part of nursing care, and also for linen changes due to diaphoresis. Irene provided anticipatory guidance for the
repositioning by instructing him that he was about to be moved but, despite doing so, he generated a significant startle response, of which Irene took note, but did not fully comprehend.

Fortunately, Mr. Jones began to improve by day two. Irene had the pleasure of meeting other family members. She described them as “incredible, they were all incredible”. Irene talked about how “fun” it was to get to know Mr. Jones as a person. Mr. Jones enjoyed running naked in the woods, which exposed him to ticks and Lyme disease; Irene chuckled slightly when she suggested that “maybe he shouldn’t be doing that any more”. Irene learned that they were an active family that ran 5Ks and half marathons together. She was also impressed that the family had discussed goals of care and “what people would and would not want in their family” despite the absence of prior critical illness experiences. She described their understanding as “they knew exactly what he would and would not want”.

Irene also learned that Mr. Jones developed PTSD following the barn accident. The information helped her connect his startle reaction to repositioning with his PTSD history. She indicated that she could “…totally recognize that now because of the way he woke up. You could tell that he was like, he was all of a sudden crazed, and then he calmed down once we talked to him, you know”.

The value of having access to the patient’s personal narrative was compared to knowing the patient second hand through the “Get to Know Me” posters. Irene talked about how nice the posters are, but felt it was great to hear about the patient first hand. She was really pleased to see pictures of them running a recent marathon, including photos of the patient and other family members.

Irene’s care was impacted by both an awareness of her patient’s level of physical fitness prior to his critical illness and the family’s goals of care conversations. She discussed his recent participation in a senior Olympic event, its reflection on his attention to physical fitness, strength
and health, and its illumination of his desire to continue living. Yet, even in the absence of a notable illness, both he and the family had discussed goals of care and their wishes to forgo any long term mechanical assistance in the face of a grim prognosis. Irene was touched by the gift of realistic decision making. She also noted the impact of family members’ presence, including the patient’s son, on helping Mrs. Jones remain committed to the prior goals of care decisions. We noted this as an exception to the norm of family members changing from previously established goals of care to allow more aggressive measures.
Irene (RN)

<table>
<thead>
<tr>
<th>Irene's Day One Focus: Establish Clinical Stability</th>
<th>Irene's Day Two Focus: Knowing Patient as Person</th>
</tr>
</thead>
</table>

Extremely unstable patient

Employed expert knowledge to treat the patient
- Managed "fluids, numbers, pressures"
- Advocated for additional fluid resuscitation despite CVP = 15

Developed beginning understanding of patient as a person from RN report

Acknowledged and catalogued patient's startle response to movement despite anticipatory guidance

Patient stability achieved, although still critically ill

Focused on knowing patient as person through patient's son
- Appreciated his unique aspects
- Appreciated level of physical fitness
- Appreciated family's prior GOC discussions

Recognized value of real person narrative

Recognized value of pre-established GOC in critical illness decision making

Understood startle as PTSD

Recognized value of family support in remaining committed to pre-established GOC decisions

Patient  ←  Irene

Family Support  ←  Son  ←  Irene
Irene’s Response to the Pattern Analysis

The transmuted diagram of Irene’s narrative beginning with their first shift together through the end of their second 12 hour care delivery period was shared with Irene during the second interview, providing her the opportunity for reflection and clarification. Irene appreciated the categorization of two distinct care delivery periods, and the way in which situational circumstances altered her approach to nursing care delivery. She did not offer any additional insights.

Irene’s Pattern Analysis Summary

Irene’s clinical expertise is exemplified through her management of Mr. Jones during day one of his MICU course for treatment of shock due to sepsis. Her skilled approaches to fluid resuscitation and pressor titration, as well as her understanding of the contribution high PEEP levels have on these variables allowed her to rescue him from profound hemodynamic instability. Irene’s determined advocacy for the addition of fluids to achieve blood pressure support represent her capacity to challenge physician authority to achieve necessary patient outcomes, placing her practice within stage three of Young’s consciousness evolution.

Mr. Jones was still very ill on day two of his MICU stay. Yet, Irene seamlessly provided nursing care to this critically ill man while engaging in family member discussions. She developed an understanding of his unique aspects including his history of PTSD, his devotion to physical fitness, and admired his family’s commitment to each other through prior goals of care decisions. Her provision of individualized patient and family centered care was aided through discovery of his personal narrative. The pattern expression of the whole is represented by the theme “Harmonizing Nursing Practice through the Integration of Clinical Expertise with the Patient Narrative”.

Participant Group Five

Patient Information: The patient was a man in his 60s who developed shock due to sepsis following chemotherapy administration, requiring transfer to the MICU. The patient was transferred to the oncology unit following a prolonged 25 day MICU stay. Linda, his long term partner, was lost to follow up.

Participant: Mr. Kane’s long term partner, Linda.

Linda’s Narrative Summary

Linda discussed the events leading up to Mr. Kane’s leukemia diagnosis. He dropped Linda off at her Boston office prior to his orthopedic appointment. She had been concerned about his breathing for the past few days, describing his breathing as a “progressive labor of his breathing pattern”. Linda was worried that something was wrong, so she wrote down questions for Mr. Kane to ask his doctor, posted the sticky note on his forehead, and told him not to call her unless he had the answers. Mr. Kane called a few hours later and, although he did not have all the answers, he told Linda that he had undergone a series of blood tests, and that he expected to be admitted to the hospital. Later that evening he called to tell her that he had been diagnosed with leukemia. Linda described her immediate emotional transition into meditation and prayers, with a focus on divine health and healing. She also reinforced to Mr. Kane the importance of being strong, fighting back, and moving into a “zone”…”you have GOT TO GET INTO A ZONE and go forward with this”. She also discussed her emotional response to his diagnosis, the care team’s openness to her questions, and her confidence in the care he was receiving:

And um, anyway, from the next Saturday morning when I got there (to the hospital) all I can say is that the experience…the first three days I was still operating in robotic form, um, doing the right things but just not really feeling anything. Um, but then after the third day, and talking to the nurses, talking to the doctors, everyone gave me their full attention, responding to questions that were being asked, and I found that repeatedly over the next several weeks. There was never a question about why are you
asking a question, or who is doing what, and then certain other things started kicking in, that the nurses did, I guess it is a 3-4 day 12 hour on 12 hour off kind of thing, and it was very clear to me, at least in oncology, and even after he ended up here (in the MICU), everyone worked in teams, and as much as I could know as an outsider, each team knew what the other team was doing. I never left here, there was not a day or morning that I left here, ‘cause those first two weeks I was her AM, I parked the car in the garage and then walked up Court Street, and then would be back here at 3:30 and leave around 5:30 or 6 o’clock, there was never a question in my mind, there was no level of stress related concern about what was being done for him as a patient.

Linda compared her current experience with that of other hospital experiences she has had, both as a volunteer and as mother whose son had a prolonged 3.5 month hospitalization following a traumatic sporting injury. She felt similarly integrated with her son’s pediatric care team, to the point of being allowed to observe the skin grafting procedures. While the physician was initially opposed to letting her observe, she convinced him by describing her successful use of hypnosis for pain management during both her delivery and hysterectomy.

Linda has been pleased with the degree of care continuity Mr. Kane has received on both the oncology unit and the MICU “…oncology and here, and the nurses and how it is set up where they have the patient for a long period of time and they get to know the ins and outs of that person…that is so key”. She questioned why a similar model of continuity is not implemented in all hospitals, analogizing health care to educational systems that fail to provide similar levels of education for all students, and expressed hope that our structures serve as role models for other healthcare facilities.

Linda has been impressed with the care providers’ acceptance of her multiple questions. She feels very informed, and highlighted the importance of information on effective decision making within the proxy role. She stated: “it is a very good experience…When I leave him as a person who has to make decisions for him, I don’t have one, not one question mark, not one, and that is
the honest truth”. She contrasted this to feelings of uncertainly while serving as the family spokesperson during her father’s pancreatic cancer and her mom’s cardiac disease.

…I wondered if something different should have been done. I wake up sometimes screaming…and then I realize that I just need to let it go. Done. Gone. But you see, his situation (Mr. Kane), with everything monitored, the less invasive type of dialysis (CVVH), to get him to a level where, now, he can maybe move back over next door (to the oncology unit) and continue to beat this leukemia thing. Totally different experience”.

Linda continued to reinforce her admiration for various components of family centered care, including its impact on both her and the lives of others.

So, um, the theoretical base that you guys work from, or the curriculum in terms of how the staff is trained, should definitely be continued and shared with other places. There should be a mandate for that…teamwork…the teamwork piece that you guys have…I find it just extraordinary….the hours…not having set visitation hours…oh my God that is so great. It made so much sense. What about the people that work night shift…what about people…you know they can’t always or they’ve got to go home and take care of the kids…and then what…and then run to the hospital, and spend 10 minutes, and then head back to work or something? So, it’s a good thing. In my opinion it is a very good thing. There is some order to what could be totally chaotic and stressful for people. And people ask if I am OK and I say I’m fine…I really am.

The importance of understanding patient and family individuality was highlighted by Linda with respect to privacy within the illness experience. Both she and Mr. Kane prefer to be alone when ill, rather than have visits from friends and family and, when this wasn’t understood among hospital mental health providers, there was an assumption that visitors would be beneficial. She described Mr. Kane’s devotion to her when she was first diagnosed with Multiple Sclerosis (MS) 10 years ago and now, in return, she is providing the same type of undivided support, but both are most comfortable relying on each other as a couple. She stated: “he doesn’t want anybody”.

Linda talked about the love and respect they have for each other, with a major focus on the similarities that foster their mutual respect.

…share what knowledge you have…share your time to help somebody else…you
know, lift as you climb...that was your responsibility to bring home good grades...same with him (Mr. Kane)...there are a lot of similarities between us. There is no excuse for low grades at all none no tolerance none. You know, and just share your knowledge, use it for good, never keep it to yourself...He has helped people get into the electrical union, the iron workers union, he has seen that kids get scholarships, he’s given them pep talks and stuff like that.
<table>
<thead>
<tr>
<th>Childhood</th>
<th>Son's Injury</th>
<th>Relationship with Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learned leadership role from family, who put her in charge.</td>
<td>Anticipated need for prosthetic device, but was not required. Calmed self by observation of and participation in son's care. Influenced positively by use of alternative therapies such as hypnosis.</td>
<td>&quot;Lift as you climb&quot; served as the philosophical bond between couple (achieve personal growth while helping others). Patient demonstrated ongoing responsibility by helping others acquire scholarships and union positions.</td>
</tr>
<tr>
<td>Linda ← Family</td>
<td>Linda ← Son</td>
<td>Patient ← Linda</td>
</tr>
<tr>
<td></td>
<td>Alternative Therapies Welcoming Care Environment</td>
<td>Community Members</td>
</tr>
<tr>
<td>Mom's son admitted her to a hospital at which her PCP and specialists did not practice</td>
<td>Felt robotic for 3 days following the unexpected and shocking leukemia diagnosis</td>
<td></td>
</tr>
<tr>
<td>Practices were not as advanced as she sees here</td>
<td>Robotic feeling resolved by</td>
<td></td>
</tr>
<tr>
<td>Experienced regret and anger. Wakes screaming, &quot;What if... what if?&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calmed by focusing on &quot;letting go&quot;...&quot;done, gone&quot;</td>
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Recommendations:
Recommend that these approaches and the philosophical foundation on which they are based be shared with other organizations and disciplines.
Linda’s Response to the Pattern Analysis

Linda did not have the opportunity to respond to the pattern analysis as she was lost to follow up.

Linda’s Pattern Analysis Summary

Linda’s individuality and determination, characteristics of Young’s third stage of consciousness evolution, are revealed throughout her experiential account of Mr. Kane’s illness. Determination is seen in numerous aspects of her narrative, including her self description of one who is outspoken and has many questions, her insistence that Mr. Kane obtain answers about the etiology of his respiratory distress, and her resolve to move him into a fighting “zone” of emotional strength. Additionally, her individuality is appreciated through her life time use of meditation, described by Linda as a concentrated approach to engaging divine health and healing for Mr. Kane after learning of his cancer diagnosis, and as a substitute for narcotics during her two prior surgeries. In fact, the later situation convinced her son’s surgeon to allow her to observe his skin grafting operations.

The couple’s value based respect for each other is clearly evident, including Linda’s acknowledgment of Mr. Kane’s community support activities, and his caring approach to her experiences with MS. Linda also highlighted her admiration for the philosophical basis of Mr. Kane’s care, and the positive impact it had on facilitating her coping skills. She noted various aspects including information sharing, continuity of care and teamwork. The pattern expression of the whole is represented by the theme: “Respecting her Loving Partner and the Family Centered Care Environment”.
Participant Group Six

Patient information: The patient was an older female with multiple medical problems who was transferred to the MICU from an outside hospital for additional evaluation of an altered mental status. She died in the MICU following her family’s decision to convert to comfort measures only.

Participants: Patient’s husband Max and MICU RN Pamela

Max’s Narrative Summary

Max described marrying at a young age, followed shortly thereafter by their daughter’s birth. His part time job did not offer health benefits, so both he and his wife held various jobs to both pay the hospital bills incurred from his daughter’s birth and provide family support. His job as an auto mechanic helped him develop related skills such as plumbing, electrical work and machine work, all of which enhanced his marketability. His versatile skills were appreciated by a family physician friend who owned a new hospital that lacked tradesmen support, and Max would always respond to his calls for assistance by doing “whatever needed to be done”. Max attributed his life long interest in his health and that of his family’s to the time he spent supporting the hospital’s technical operations. His career expanded into a police officer reservist role, and then to General Electric, where he advanced from janitorial work to become a technical writer for jet engine manuals.

We were married young; and we had a child almost immediately; didn’t have a full time job; and did a lot of things to get by. She worked...ah, usually her work was night work; mine was day. And then I switched to nights, so we had to get a babysitter...both working nights, she managing a Dunkin Donuts for a little while and uh I spent a lot of time at different jobs...mostly as an automobile mechanic. What most people don’t realize about automobile mechanics is that they are plumbers, they are electricians, they are tin knockers, they are machinists; there are a lot of things you need to do to be an automobile mechanic. But I also did a little short order cooking, uh, she spent a year in Burdette College in Lynn...I didn’t spend any time in college at all ah I did take some night courses. Ah, we stayed with her family for a long...quite a while when we first married and, ah, we finally got our own apartment... except we couldn’t afford it (chuckles) ah at one point I... ah.. well, with the mechanic’s job we were living at that time in Saugus...they had opened the Saugus General Hospital and the doctors got together and bought a building and created Saugus General Hospital.
They didn’t have much money…they had a lot of money but they had invested most of it in the purchase and so the staffing was low, and the equipment was used…in today’s sense it was pretty primitive ah and one of the doctors who was involved in the purchase was a personal friend of ours, my father’s…he used to spend his spare time around my garage because he liked cars…so that when they got involved in the hospital he would occasionally need some help at the hospital, because he didn’t have any people other than nurses and the doctors themselves so, ah, when the nurse was in trouble and needed help, they would call the garage and one of us would wash our hands to get rid of the grease and the oil and run up there…it was only less than a quarter of a mile away but we would always drive up to get there in a hurry and uh do what ever they needed done. I can remember specially, several times ah we had to go up (I’d go up) and lift the bed so the nurses could put the Coke bottles underneath the bed because the new mother was hemorrhaging. They didn’t have any fancy beds in those days…they just had straight twin beds and in order to get the foot up or the head up they had to lift them and stick Coke bottles underneath the ends, so they could get the beds where the nurses’ needed them. But any time they had some patients that, ah, looked like they might need help I usually went and my father contributed to it but, every once in a while somebody else would do it and go up and stay in the hospital overnight, and sleep on old gurneys or whatever you could find to sleep on… ah, be there in case they needed help and we woke up every hour of the night of course. That was, I thought, very interesting and I think that’s where I come up with paying attention to what is going on in the hospital health wise for both of us, and our kids. Ah, I eventually took a police exam and became a reserve police office for about 7 years. When they offered me the full time job I just had a job offer from GE paying a lot more money; I took that instead. But even after I went to GE, I was still working part time (as a police officer), covering shifts doing private traffic control and all that stuff for the police department.

As hard working and loving parents, their lives were devoted to both raising their children, including two boys born ten and eleven years following their daughter’s birth, and providing family financial support by working various jobs. Max spoke proudly of his children, describing them as “three of the best kids you would ever want to meet”. He discussed their successful careers in diverse areas such as the ministry, carpentry, music and auctioneering.

...my daughter is a retired office manager for one of the largest auction companies in the area. She started out with us (in the auction business). And our son, our youngest son started out with us and became the manager of the auction company, the same auction company she was with, and the other boy worked a variety of jobs and eventually heard the calling for the ministry and he went to Colorado eventually and became an ordained Nazarene minister which he still practices today, as well as a custom wood worker… ah, he tried it on his own and it didn’t pan out for him, not that
he didn’t do good work but he spent too much time so the prices…ah, he couldn’t sustain the length of time it took to sell the product. He made us a lot of our furniture. He (another son) now sells musical equipment, electronic accessories for stringed instruments…pick ups and amplifiers and loud speakers and stuff like that. He is the national retail account manager for a very large company here in Andover and doing extremely well. Has a little three piece band and plays out on weekends, and one of our things is, whenever their band plays is, we’re not rock and rollers but we didn’t care what it was, we went to support him and listen because we enjoyed it. He is a guitar player and extremely good. Well thought of in the industry. Travels all over the country to do shows…manufacturer shows with his equipment and spends a lot of time, they like him because he actually knows how to use the equipment.

Their family life focused on supporting the children’s activities. Max and his wife transported the boys’ to their athletic games, where they both were varsity players, and to band competitions. The parents ran children’s dances at the local YMCA, and became leaders in their church’s Sunday school. Attendance at Sunday school grew dramatically once other children realized that two of the school’s best athletes (his sons) were “cool” enough to participate in Sunday school.

The youngest boy.. they both (both boys) played in sports, very active in sports, and we supported them, we lugged them around, ah, our son, both of them were very productive in baseball and football. I think one of them has a record still with the high school for his participation…a record that still stands. They were both on varsities; both exceptional ball players. Ah, the youngest son like I said was very interested in music, And during the high school from junior high through high school we use to have to transport them to the “battle of the bands” I don’t know if you are familiar with that, it’s high school kids and four or five bands, it is all rock and roll at the time and, uh, we hauled them and their equipment all around.

Our interview was interrupted by the senior medical resident, who discussed Max’s wife’s declining respiratory status and her potential need for reintubation. Max was very clear about her wishes, including the desire to avoid nursing home placement and any heroics, but he was willing to re-intubate if the physician thought there were elements of her current condition that could be reversed enough to allow her to resume her prior activities. The senior resident indicated that she was not sure what was causing the current deterioration but, to make the determination, she would
need time to perform various tests. Max agreed to the re-intubation. He then comfortably resumed our conversation, which I found surprising. When I explored this with him, he reflected on our dialogue as an important legacy for his children. We continued the interview.

Max recalled his stock car work. This, also, was a job he held early on in their marriage, shortly after their daughter’s birth. He and his wife would attend weekend races, placing the baby on a shelf in their ‘34 Ford, watching her carefully as they sat in the bleachers cheering on their favorite drivers and stock cars.

Engagement together in family activities continued as their lives progressed. Max stated “…we have always done things together…” The couple became interested in auctions, as items were more affordable than retail store prices. This evolved to an interest in antiques and participation in antique shows. Auctioneering was run as a family affair, involving children and grandchildren. The couple also attended craft fairs, where his wife displayed her folk art creations and Max would do the “talking and selling”. Max stated:

So it was pretty much a family affair and that’s the way we ran it. We didn’t run it to make a ton of money, we ran it so everybody was picking up a few dollars a week and we had, we were all together as much as we could get together. That is pretty much the way we lived our lives. Everything we did we did together.
### Participant Group Six

Max (Husband)

<table>
<thead>
<tr>
<th>Preparation for Professional Life</th>
<th>Juggled careers to provide family support</th>
<th>Loving parental involvement produced three wonderful children</th>
<th>Continued integration of family with careers</th>
<th>Wife's critical illness</th>
</tr>
</thead>
</table>

- Husband graduated from high school
- Patient attended Business School
- Husband worked as auto mechanic, assisted at local hospital and established long career at GE
- Patient worked at various enterprises (Dunkin Donuts, Woolworths, Mammoth Mart)
- Children involved in sports; music, scouts, Sunday school, YMCA, dances
- Achieved careers as an office manager, minister and carpenter; and musician/sales manager
- Remained connected as a family (children and grandchildren) in activities including stock car racing, auctions and folk art
- Multiple medical problems
  - Max clear regarding goals of revalidation (reverse illness enough for wife to resume prior activities; avoid heroic and nursing home placement)

- Husband → Patient
- Husband → Patient
- Parents → Children
- Parents → Extended family
- Parent → Max
Max’s Response to the Pattern Analysis

The transmuted diagram of Max’s narrative beginning with his marriage and progressing through their family life experiences to the point of his wife’s critical illness was shared with Max during the second interview, providing him the opportunity for reflection and clarification. He expressed interest in the diagram and validated the timeline. However, his additional insights occurred at the conclusion of our first interview, prior to the sharing of the diagram, when he noted that his capacity to remain true to his wife’s goals of care was due to the fact that they have lived a life of mutual support, a concept which emerged strongly throughout the interview. For Max, supporting his wife’s goals was an extension of the way in which they have lived their lives together, and his selfless devotion to others.

Max’s Pattern Analysis Summary

Analysis of Max’s narrative demonstrated a pattern of selfless devotion to friends, his wife and their family, including children and grandchildren. Max consistently reframed his work from simply a means of family economic support to ways in which he could serve friends and family through lasting and meaningful connections. Max’s unwavering dedication to others represented a life positioned in the fifth, or de-centering, level of Young’s consciousness expansion model. The pattern expression of the whole is represented by the theme “Selfless devotion to spouse, family and friends”.

Participant Group Seven

Patient information: The patient was a young woman who transferred to the MICU from an outside hospital for treatment of recurrent pneumonia. She survived her MICU admission and was subsequently transferred to the general care unit.

Participants: Patient’s mother Rose and MICU RN Stephanie
Rose’s Narrative Summary

Rose characterized herself during the early phase of her marriage as a “quiet housewife”. She and her husband first welcomed a baby boy into their lives and then, four years later, Rose gave birth to a healthy baby girl. Their daughter quickly achieved developmental goals until age one, when she contracted meningitis, resulting in severe brain damage. Rose noted that she was never exposed or understood the world of a person with disabilities until her daughter became disabled.

Rose experienced a major transition during her daughter’s two months of hospitalization. In her words: “…she went in at 12 months old, and we didn’t come out till she was 14 months old; that was 2 months later. So, in two months, you learn a lot too”. Rose’s most significant discovery was the depth and breadth of her maternal devotion. She described it as emerging rather suddenly during a conversation with her daughter’s physician, who suggested the option of institutionalization while acknowledging Rose’s capacity to conceive other children. Rose was shocked by this suggestion, and described the encounter as the point where everything changed. She responded to the physician by asking “are you crazy? She went on to say “…she is mine; she is my child…I think my devotion started right then and there”. Rose acknowledged this as the point where she committed to serving as her daughter’s “champion” and one which catapulted her out of her quiet housewife role. She also recognized her need to acquire an entirely new knowledge base to effectively care for her daughter. While she appreciated that providing care to a developmentally disabled child was completely outside of her comfort zone, she had faith that her maternal role and bond would consciously direct her work. In Rose’s words: “…I decided, you know what, this is something that, I, I don’t have a calling for but I am going to make myself…this is going to be my world.”
As Rose carried out her roles of wife and mother, she acknowledged major differences between her and her husband’s perceptions of their daughter, and appreciated early on that her husband would not be able to reconcile his life as the father of a disabled daughter. While he felt sorry for her, his emotions were distant rather than paternal. Rose’s husband expressed his feelings using expressions such as “poor child, poor child”, to which Rose responded “…what do you mean ‘poor child’, she is your daughter”. Rose understood her marriage would not survive, but she continued forward. One area of focus was on providing her son with “everything”, including her love, the best schools and opportunities to participate in extracurricular activities including karate and cub scouts. Yet, unlike her daughter, she knew her son would be fine in the world.

A part of Rose’s work was selecting the most appropriate infant stimulation programs for her daughter, irrespective of the required driving distance. She described feeling insecure about these decisions, employing feelings to help guide her decision making processes. She stated “We went to many programs and, if I didn’t think they were doing right…oops, let’s go somewhere else”. Further, Rose obtained a position in a local special education department to learn about types of funding for which her daughter could qualify. Throughout this journey, Rose remained open to and welcoming of new ideas. One new learning strategy (patterning) aided her daughter’s mobility by redirecting her from only crawling in right hand circles to crawling straight. Rose described this as a revelation, realizing that her daughter had retained some capacity to learn “in her own way”.

Rose’s son has grown into an intelligent and professionally successful young man. Now living out of state, Rose described him as wonderful, and very devoted to his sister. Yet, he is clear about his inability to serve as her long term care provider. Rose acknowledged this respectfully and gracefully. She stated “…and I have decided to respect his wishes, because that gives him his life, and that is OK. As long as I know he is there; I know where he is, and I know he’s happy, that is
all I care about”. In addition to raising her son, Rose described other components of her life, including acceptance of her daughter’s illness and subsequent brain damage, engaging in an amicable divorce from her husband, and finding a new life partner of 19 years, whom she plans to soon marry.

As the mother of a disabled child, Rose needed to consider the type of advocacy style she felt most comfortable embracing. She described the demanding, group approach as one which she has decided to reject. Rather, she employs quiet connections, allowing paths to unfold. She has learned the importance of clearly stated expectations embedded within the existing system, the importance of being nice in any crisis, and the value of offering respect while expecting the same in return.

Rose transferred her daughter from their local hospital to the MICU at the recommendation of their primary care physician for treatment of her recurrent pneumonias. She described numerous challenges of leaving their home routine for the “foreign land” of hospitals, including being either accepted or rejected by health care providers as she imparts knowledge of her daughter’s needs.

Some people say ‘what a nice person you are, what a devoted parent’ or ‘what a but-in-sky, I’m going to have trouble with this one’. It is not meant to be that way. I mean I am the holder of information here, and I am not saying that I do things the right way in the hospital, because I have already gotten, I’ve met with many people who say ‘well, when you are in the hospital you do it our way’ and things like that. But nobody should be made to do something they don’t understand…I am not a genius, I don’t know everything. I know how to take care of her at home.

She was relieved to discover that she is recognized and embraced by the MICU staff as a knowledgeable and caring mom and, because of this, has felt trusted and respected. Also, she is pleased to be invited into care conversations including rounds. Rose described her perception of rounds as a deeply caring community of individuals gathering to focus on one patient at a time. Indeed, her recognition of a subtle behavior change and the opportunity to discuss this during rounds let to the discovery of a dosing error.
…a lot of the nurses here have said “you are a wealth of information; we enjoy what you have to tell us”. Well, we didn’t know that. I already caught a mistake from yesterday (by being present in the care environment and in rounds) I said OK, well the Gabatril (one of her seizure medications)…well guess what… Gabatril comes in 4 mg…just to give you an example…4 mg tablets…this is of the many that she takes…but Gabatril was an example. Gabatril is a medicine she has been on for two or three years…it’s a medicine…but that’s not the issue….the issue is that it is a 4 mg tablet, so it is supposed to be 6, 4 and 12 (mg)…and that means the dose in the morning will be 1.5 tabs, right, because that will make 6 (mg). And then the one tablet because it is a 4 mg…remember, they only come in 4 mg …and then three 4 mg tablets at the end of the day. Well, somebody made a mistake here, already, and I said to them…how is her Gabatril…is there something going on…because I knew we were going to be in touch with the neurologist and I know what her pills and things due…I already know her…I know what the reaction is going to be…Um, they didn’t say that the neurologist back home increased it….so why does it read…I saw on a piece of paper that it was 8 in the middle of the day…it is not 8, it is 4…because she was a little bit groggy the other day…so, for the last two days, is it the…when they put the…what do you call it…intubation…they give her some type of sedation… OK, is the sedation still lingering, here, or is this something going on…now this is just the eye that I am looking at, because I am looking at her and she looks kind of…sleepy….not all the way, she is watching TV, but I see the way her eyes are and a certain way…and she looks a little bit sleepy…sort of what she looks like when she takes over medication, because this has happened before. So they check and say, “oh yes, we are giving her 8” (instead of 6 mg), and I say yes, OK…so the doctor changed the order, and now it is perfect…it is 6, 4 and 12. That’s just…it is just a little thing…it was just my intuition that I see her…and she seems just a tiny bit off. This is what I do…I look at her.

Yes, and I said that in front of Dr. (Attending Physician), I think I said that…”ummm, she seems a little bit, ah, funny…you know I call it “funny” when she is off… not that she is off, that is another word, but she just seems,„ a little bit tired at the end of the day…and I said, “you know what, can you just check her meds?”, and that is when they said, “well, she is getting 6,8 and 12”, and I said “oh, wait a minute…”. Go back to the…and sure enough. So she should be herself in another day or two, because these meds are powerful meds, and they do things to you. So that is just a little example, and that is when we are here.

Yet, the burden of decision making has weighed heavily on Rose, as she worries deeply about how her decisions will affect her daughter’s life. Rose revealed that she wanted to discharge her daughter on day three of her MICU hospitalization when the need for intubation surfaced.

Um, so, here I am, I wanted to leave Wednesday when they brought me the papers for intubation…I said “oh my God” what am I doing to her? Everything I say is “what
am I going to be doing to her? You know and I just have to pray that I am doing the right thing. I am not saying that…I am not saying that…I don’t know if I could do it again…I did it then…and we are here…and she is better today…but at the time you know when the doctors ask you to do something and everything seems so fast…her life depends on it…and I do sign, but it is like, it is a lot of decisions to make for somebody that is so helpless and can’t take care of themselves…and I mean I don’t ever want to do anything to hurt my daughter…I do it with the most spirit and the most love…and I am hoping that whoever I give her to, to do the procedure, can look at it in that way, because it takes a lot for me to make the decision, you know, they come around with papers and say “sign here” and then they leave and thank God I hope these people realize that there is another me…I am the human being behind the curtain as they are doing the procedure, and they are doing it to her, they are doing to me, but in a different way, because if they fail and don’t do a good job, you can imagine how I am going to feel.

Rose initially felt overwhelmed by the waiting room, but this feeling quickly transitioned to an appreciation of its mutually supportive atmosphere. She described her cautious acknowledgement of other family members while offering sensitivity to their privacy needs. While the clinical problems of others served as a unifying element among family members, Rose also felt worried and concerned that her daughter would experience similar outcomes such as challenging complications or even death. Rose described how the realities of other family members helped her to appreciate them as a new community, lessening her loneliness. Rose now felt a sense of equality as a member of this new community, a distinctly different feeling from her usual sense of isolation as the mother of a disabled child. Rose acknowledged the beauty in this community of strangers. She also made an astute assessment of their common threads, including the pleasure associated with being cared for at this hospital, concern about each other, and various hopes including the hope for another chance with their loved one, hoping for the best and hoping to feel good again.

Um, you know, here in the waiting room, I came on Monday, today is Saturday. I have been here since Monday…first of all….you know, in the beginning….oh my God…look at all these people… anybody that is there (in the waiting room) obviously has somebody in the ICU…OK….that is without saying….well, if that is the case, then you look around, I am in my quiet little space, with (daughter)’s wheelchair and her
possessions next to me, and it's hard to look at somebody because they look nasty, they don’t want to look at you, they have their own grief to attend to. You know, you look at them because you want to acknowledge another human being in your presence, but you don’t keep your eye on them you look away, and with a smile, you look away, and everything is OK. You don’t mean to invade anybody’s privacy because that is a no no, because…you know…it can be really nice, you know…some people have really opened up, you know, just ah, the last week…“are you here for someone”…I say “yes, my daughter”…“oh is she OK”…“well, she had a tube down her throat”…“oh my God the tube”…“and my mother, they don’t think my mother is going to live”…and, once they say something like that…it hurts me to hear that, because I think to myself, oh my God, is (daughter) going to die? And then I say “well, I wish you luck” and everything, and they say “yes, I know, the doctors don’t give her much time”. So, even though you don’t want to be drawn into something like that, you can’t help it, you are right there with those people. And it isn’t you that is the universe…you are not the universe any more…and there are a lot of people out there that are hurting…and some of them…all they want is just another chance with their loved one. And I mean when I brought (daughter) in on Sunday, I was filled with tears, because I didn’t even know (daughter) had her third pneumonia so, for me, to see (daughter) weak, it makes me weak. I don’t want to be weak, but I can’t help it. And so, you hear somebody talk about their loved one, it is OK, but you know you have to listen to them too, but it hurts when they really go into detail. You don’t want to hear, but you have to, because you are looking right at them…how can you walk away. But you know, in this hospital…the one common thread…everybody is so glad to be here. There is lady from Rhode Island, another one from Virginia, another one just got off a plane from Seattle…and I am just over the boarder in (names NH town in which she lives)...Yekes…isn’t that something…(laughter) I am just right here…so that is such a positive… nobody is here saying “oh, I shouldn’t be here”. There is a common thread among everybody that goes through (that waiting room). You are a professional (participant/researcher), so you are not a part of that universe, you see, in this universe…but everybody that I have met, from Monday through Saturday, so very positive and even though somebody has lost a loved one… I see them go back and forth…and they say “how is your daughter…how is she doing” and I am asking about “how is your brother; is he OK?” It all of a sudden everybody is concerned about everybody else…without them knowing it…you know what I am saying…we are all concerned about the person sitting next to us…I don’t even know her last name…but we are very concerned and we will keep you in the prayers…it is a beautiful thing that is going on.

The participant/researcher noted that her description made the waiting room atmosphere sound like a community of strangers. Rose responded:

It IS it is…right here…right at your back yard…isn’t it something…as I say, I go back to the waiting room…a lot of people don’t even know my name but we all know each other by the symptoms of everybody (she lists a father with a heart attack; a brother with diabetes; we chuckle)... it is not invading our privacy… it is just talking about this issues… that’s how we know… you come in and “how is your daughter
today?” and it is really nice to see that…so we have a community of strangers with um different malaise, or what ever you want to call it…and that is what we focus on…”how is she today…oh, the tube came out? how wonderful!”. I still don’t know that person’s name, but you have a little support system there, because you took the time to smile and be nice to somebody who, at one o’clock in the morning was sitting there, catatonic like, thinking about their mother and here you come with your pillow and, you say “can I get you a glass of water?” or something like that, you know, you just have to be so nice. I think this all has to do with being nice in a crisis. You know, because if you are not nice in a crisis, you know with everything that is going on in this horrible world today, and I mean horrible with the things that go on, you live your own little sheltered life…secular little life, and you take care of your own… it is nice to reach out to people but people don’t reach out to people who are disabled or who are not perfect, you see. So you find yourself very alone…that is why that waiting room is such an inspiration, because every body in there is not perfect, every body is mourning somebody… everybody has someone in the ICU. And, you know, in the beginning I sat there and I said, I’m by myself, but I am not by myself.
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<td>Gave birth to first child, a son</td>
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<td>Gave birth to daughter four years later</td>
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<td><strong>Mowing forward raising 2 children, one of whom was disabled</strong></td>
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- Became daughter's champion
  - Realized husband could not father their disabled daughter, but continued on with marriage
  - Loved son, providing him with excellent schools and activities
  - Developed expertise at knowing her daughter's behavioral signs
  - Remained open to new childrearing ideas
  - Embraced role of doing right for daughter, and learned how to negotiate avenues for her
  - Experienced joy realizing her choice of developmental advancement programs enhanced daughter's cognitive performance

- Connect quietly
  - Let the path unfold
  - Be clear
  - Work with system
  - Offer respect; expect the same
  - Be nice in a crisis

- **Positives**
  - Embraced as a knowledgeable mom by care team; one that knows her daughter
  - Invited into care conversations
  - Felt trusted and respected
  - Her expert knowledge of subtleties revealed a medication error

- **Negatives**
  - Burden of decision making (intubation)
  - Worry about impact of decisions on daughter
  - Deeply connected to daughter as one; her clinical condition (+/-) experienced similarly by Rose
  - Rollercoaster of emotions

- Rose ➔ Daughter
  - Husband ➔ Son

- Rose ➔ Disability system ➔ Rose
  - MGH MICU ➔ Daughter
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<th>MGH MICU Waiting Room</th>
<th>Common threads: 1. everyone grateful to be at this hospital 2. everyone just wants the best 3. everyone is waiting to feel good 4. everyone is concerned about each other 5. everyone just wants another chance with their loved one</th>
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Overwhelmed by so many people
Cautious acknowledgement of others
Sensitivity towards others' privacy
Clinical situations connect self to others
Others' worries become your own..."is my daughter going to die too?"
Development of mutual concern
Became a beautiful experience
Developed into a community of strangers
Leveled the field such that daughter's disability is no longer a barrier to others' reaching out; others reach out around the illness, which helps to curb the loneliness

| Rose | Family members in the waiting room |
| Rose | Family members in the waiting room |
| Rose | Family members in the waiting room |
Rose’s Response to the Pattern Analysis

The transmuted diagram of Rose’s narrative beginning with her early married life, progressing through life transitions and concluding with her MICU waiting room experience was shared with Rose during the second interview, providing her the opportunity for reflection and clarification. Rose achieved additional insights during this process, which she attributed to reflections following the initial interview, and the participant researcher’s interpersonal approach. They included:

A) The need to focus on her on physical health. Rose neglected her own health lately, missing physical examination and mammography appointments. She realized the need to maintain her own health, and made a commitment to attend to these needs.

B) The desire to reunite with her brother and sister, both of whom where estranged from their parents. Rose articulated the importance of renewing these connections.

C) The plan to refocus on her relationship with her partner, including seeking Hospice assistance to help him mourn her father’s death. Her partner was very close to her dad, who just recently died. This was quickly followed by the MICU transfer, and refocusing their attention towards her daughter’s illness. Rose realized the importance of revisiting the mourning process for her dad, and the need to assist her partner to join in this work.

Rose’s Pattern Analysis Summary

Analysis of Rose’s narrative demonstrates her unwavering maternal bond accompanied by a pattern of remarkable and gracious life long learning and giving to others. A choice point was experienced when her daughter’s physician suggested the option of institutionalization. Rose emerged from this discussion with a new found commitment to serving as her daughter’s life long champion. Rose understood her daughter as a culmination of her heart and soul, rather than a disease state. Young describes the stage four choice point as a turning point responded to with
awareness, inner growth and the development of new solutions. Rose has never abandoned this commitment, embarking on understanding of her daughter’s patterns and developing them to the limits of her learning capacity. Her ongoing dedication to others is reflected not only through her daughter but also in her commitment to raising her son, caring for her ailing father in her home until his recent death, recognizing the need to support her partner’s mourning, her sensitivity to others in the family waiting room and her new decision to renew fractured ties with her brother and sister. The pattern expression of the whole is represented by the theme: “Finding the way with devotion and grace”.

*Stephanie’s Narrative Summary*

Stephanie described the patient as a young woman in her 30s with cognitive and physical limitations. Although previously high functioning, the patient had suffered declines throughout the past year due to multiple episodes of pneumonia. Consequently, she was no longer able to eat and required a feeding tube for nutritional support, both of which were perceived by her mom Rose, the patient’s primary care provider, as a loss of independence. While still trying to cope with this development, the patient’s local provider suggested tracheostomy placement as an intervention for her ongoing episodes of respiratory distress. Mom thought the recommendation for tracheostomy placement was too premature, and Stephanie perceived mom’s concern to be based on a sense that the provider was taking the easiest approach for her disabled daughter. Rather, mom felt that her multiple home services could be harnessed to employ an alternate approach that would preserve her daughter’s functioning at the current level. Stephanie appreciated mom’s willingness to devote 150% to avoid a tracheostomy, as having an artificial airway would prevent her from riding horses, one of the many activities her daughter enjoyed.
Stephanie admired mom’s advocacy, and dedication of “everything” to provide the best opportunities for her daughter, so that she could have the “the most normal life that she could potentially have”. Mom shared specifics of her daughter’s lifestyle, including horse back riding, watching movies, attending school, and developing friendships with others. While Stephanie was happy to learn about unique aspects of her patient, she wondered if mom was trying to emphasize that the patient was a person, rather than “just a disabled person that doesn’t think or have emotions or anything”. Stephanie discussed her appreciation of mom’s experiences, and nursing’s acceptance of all patients, irrespective of their functional capacity.

...she totally understands that I would never think that way and unfortunately I know that can be a feeling of people, you know, it is a hard thing to deal with, her mom felt that if she was viewed as a disabled person, her life wasn’t worth as much as someone who was high functioning. So I felt like her mom always tried to constantly remind us of everything she was able to do and could do and enjoyed, just so we really saw her and looked at her as a person who we wouldn’t treat her any other way which, we feel, we do that to everyone no matter what, and always have their best interests in mind, and try to keep, to get them back, I feel like our goal is to always get the person back to whatever their functioning was before their admission or, you know, even further, if possible, if we can figure out the best treatment plan. I don’t know if it was experiences she had in the past, or just her own feeling of insecurities about how the world views her daughter, but that was a big thing; her mom really felt like she had to be there and tell us how great she is. It was nice to see, how loved she was, and it is amazing to me, her mom would just go to bat for her for everything, so it was nice because, you could really see, her skin was immaculate, and she had all these toys, and she really responded to her mom.

Stephanie appreciated the trauma associated with mom’s experiences at the outside hospital. The patient was desaturating due to secretions, and required blind nasotracheal suctioning for secretion clearance. This was accompanied by the use of forceful hand restraint to prevent her from resisting the intervention. Mom felt she was torturing her child, whose eyes communicated her distress, but who could not understand the necessity of these clinical interventions. Stephanie knew mom felt much more positive towards us, as the local hospital recommended transferring her
daughter to a tertiary facility but, in response, Stephanie acknowledged a sense of pressure placed on her and her colleagues when encountering hopeful family expectations. In her words:

…oh my God, you really want to just be able to succeed, you know, during the hospitalization and help them to move forward, and you just want to fulfill, to live up to everything the mom was hoping that we were.

Mom was devastated when she learned of her daughter’s need for intubation; Stephanie described her response as complete collapse. Yet, Stephanie recognized mom’s misconceptions, including her perception that the endotracheal tube and tracheostomy were the same, and her belief that an endotracheal tube meant that a tracheostomy was unavoidable, both of which were corrected through Stephanie’s teaching and explanations. The decision was made to proceed with a planned intubation, as it was clear that the patient would very likely experience a sustained desaturation from which she could not be rescued, thus reducing the risk of a traumatic, emergent intubation. Stephanie described her approach with mom during the intubation:

…I thought it was a genius idea (we chuckled together) but, we gave her the “Get to Know Me” poster to do, ‘cause she had all these pictures of her, so it was a perfect time, so we said this is your activity, don’t worry about this, like we have everything, we have specialists that are coming that do this all the time, so they are going to come it, it is going to be a very calm environment. Now, this is your job (completing the poster) so everyone can know what your daughter does, what she likes to be called, who she is, everything …she went to town on that. It was nice. And she really referenced that board (poster) for everyone; she said she wanted everyone to feel how alive and active her daughter was. It was good. I think it was really less traumatic for her mom so, in the event it would need to happen again (an intubation) she wouldn’t have such negative feelings about it that is was so awful…

Although the patient was successfully extubated for the duration of her ICU stay, preventing a subsequent intubation was not easy. Stephanie acknowledged this patient’s ongoing airway management struggles, and her likely need for a tracheostomy, but also knew that mom had misconceptions about its influence on her daughter’s life. For instance, she realized that mom thought a tracheostomy would prevent her daughter from returning home, leading her to envision
her daughter receiving custodial nursing home care. In response, Stephanie provided mom information and support around these issues.

Stephanie concluded by reflecting on this situation as one where she felt she made a difference in the lives of this patient and her mom. The patient moved to a local rehabilitation hospital, accomplishing her mom’s goal of connecting with a physical medicine specialist at this specific facility. Given her first hand knowledge of mom, Stephanie appreciated her capacity to fully absorb the lessons learned at rehab, such as cough assist devices and other rehabilitation tools, to provide her daughter every chance at maintaining her functional capacity. Finally, she talked about the recent death of Rose’s father which, while devastating, liberated Rose from his care giving responsibilities and provided her time to devote towards her daughter’s recovery. Stephanie’s final gift was to provide chaplaincy support, which Rose found extremely comforting as she began to process and grieve her father’s death.
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<th>Stephanie's understanding of the clinical situation</th>
<th>Stephanie's understanding of Rose's contributions and life perspectives</th>
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| Clinical decline during past year                | Amazing dedication to daughter                                      |
| Required G tube                                   | Providers may be less aggressive in light of daughter's cognitive limitations |
| Three episodes of PNA                            | Assuring care givers that she could offer care and services aimed at retaining her daughter's function |
| Need for intubation                              | Recent death of Rose's father                                       |
| Requirements/Interventions necessary to prevent re-intubation | Highlighting her daughter's unique personhood                        |
|                                                  | Highlighting her daughter's life as worthy                           |
|                                                  | Hopeful for more sophisticated interventions compared to CSH          |

Stephanie → Rose → Patient

Stephanie ← Rose ← Patient

Stephanie ← Rose ← Rose's father
Stephanie’s interventions situated in an understanding of Rose’s experiences and her daughter’s clinical situation

| Assured belief in Rose’s daughter as worthy |
| Assured Rose of her dedication to help achieve daughter’s highest level of functionality |
| Appreciated the perception of nursing interventions as traumatic to Rose |
| Educated Rose to help reframe her misperceptions about endotracheal tubes and tracheostomies |
| Employed planned approach to intubation with everyone, including Rose, having a role |
| Affirmed hopeful future, even if tracheostomy required |
| Provided Chaplaincy support for Rose to support her grief work regarding her father’s recent death |

Stephanie ← Patient
Chaplain ← Rose
Stephanie’s Response to the Pattern Analysis

The transmuted diagram of Stephanie’s narrative, addressing her understanding of the patient’s clinical situation along with mom’s contributions and perspectives, culminating in her situated interventions for both the patient and her mom, were shared with Stephanie during the second interview, providing her the opportunity for reflection and clarification. Stephanie appreciated the diagrammatic categorizations of her nursing care delivery, but did not offer any additional insights.

Stephanie’s Pattern Analysis Summary

Stephanie’s narrative analysis reveals her devotion to both this patient’s care and to addressing the meaning embedded within this mother-daughter relationship. The individuality of her practice is highly apparent, placing her within the third stage of Young’s consciousness expansion model. She confidently established a plan based on the patient’s airway management needs, provided teaching and support as mom began to absorb her daughter’s changing clinical picture, and redirected mom away from fear and towards helping clinical staff achieve a better understanding of her daughter as a person by her completion of the “Get to Know Me” poster during the patient’s intubation. Newman notes the importance of orchestrating interventions to achieve the most advantageous growth and change, all of which can be appreciated through Stephanie’s narrative. The pattern expression of the whole is represented by the theme “Nursing Devotion to Achieving Best Outcomes for a Vulnerable Patient and her Maternal Care Giver”.