

THE SUFFERING JOURNEY: LIVED
EXPERIENCES OF PERSONS WHO HAVE ENDURED
LIFE-IMPACTING SUFFERING EVENTS

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This is dedicated to . . . all those who suffer:

Is it nothing to you, all you who pass by? Look around and see. Is any suffering like my suffering that was inflicted on me, that the LORD brought on me in the day of his fierce anger? From on high he sent fire, sent it down into my bones. He spread a net for my feet and turned me back. He made me desolate, faint all day long. (*Lamentations 1:12-13, The Holy Bible: New International Version, 1984, pp. 796-797*).

Because of the Lord's great love we are not consumed, for his compassions never fail. They are new every morning; great is your faithfulness (*Lamentations 3: 22-23, The Holy Bible: New International Version, 1984, p. 799*).

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THE SUFFERING JOURNEY: LIVED EXPERIENCES OF PERSONS
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ABSTRACT

Suffering is a frequently unacknowledged and complex phenomenon in health care settings despite its centrality to every patient's health care experience. Patients' journeys of suffering due to illness are often compounded by ancillary suffering issues that further intensify their complexity. Health care professionals tend to ignore or minimize how suffering experiences influence illness and their impact on patients and families. Many professionals talk "around" suffering when interacting with suffering patients and families while failing to address its significance in their illness experience. Those professionals who do recognize its existence often struggle with how to offer supportive care while balancing suffering's toll on their personal and professional lives. Suffering is a key phenomenon impacting clients' decision-making processes, but it is often not the basis for healthcare professionals' care and interventions. There is a critical need for health care professionals to discover the significance of their clients' stories of suffering, and to unravel suffering's meaning and its impact on their patients' healing, health care experiences and decisions.

The purpose of this study is to describe the essence and meaning of the lived experiences of suffering for those who have endured life-impacting events. This interpretive study will take a phenomenologic approach to examine diverse suffering experiences based on participants' deep reflection of descriptions of their suffering

journey compared with their experiences of enduring. Additional reflective exploration will include the impact of suffering on one's life, significant support received from others, support that was desired but neglected, perceptions of healing in suffering, and self-discovery gained through suffering.

The investigation, grounded in relevant literature on suffering, begins with the assumption that suffering is a universal yet highly individualized phenomenon. The purposive, intensive sampling design will seek participants with maximum variation, but limit deviant case sampling. Two open-ended interviews, at one month intervals, will be conducted in natural settings with up to ten participants until data saturation is achieved. Participants may be asked to journal their responses to questions prior to the first interview to promote deep reflection. Member checks will be achieved through focus group sessions following an inductive data analysis. An audit trail will be conducted.

Due to the centrality of the suffering experience in healthcare and relative lack of effective caregiver strategies, this study has potential to enhance professional caregivers' assessment of enduring and suffering, and may lead to the discovery of more effective and innovative supportive care for suffering clients and their families.

THE SUFFERING JOURNEY: LIVED EXPERIENCES OF PERSONS
WHO HAVE ENDURED LIFE-IMPACTING SUFFERING EVENTS

CHAPTER I: INTRODUCTION

Purpose of the Study

The purpose of this qualitative, phenomenological study was to explore the essence and meaning of the lived experiences of suffering for persons who have endured life-impacting events.

Research Question

The study was devoted to understanding the essence and meaning of the lived experiences of suffering by examining this question: *What is the lived experience for persons who have endured life-impacting suffering events?*

The specific aims of this study included:

1. Describe the lived experience of suffering for individuals who have experienced and endured various types of suffering and life-impacting events.
2. Distinguish between the experiences of suffering and enduring due to life-impacting events.
3. Explore perceptions of healing and alterations in self-perceptions for adults based on the lived experience of life-impacting suffering.
4. Enhance professional caregivers' assessment of enduring and suffering; and discover effective and innovative supportive care for suffering clients and their families.

Background and Rationale

Suffering is a frequently unacknowledged and complex phenomenon in health care settings despite its centrality to every patient's health care experience. A lack of

focus and limited research on the phenomenon of suffering exists (White, Wilkes, Cooper, & Barbato, 2004) in relation to the exploration of the deep meaning of suffering on persons' lives. Patients' journeys of suffering due to illness are often compounded by ancillary suffering issues that further intensify their complexity. Yet, health care professionals tend to ignore or minimize how all types of suffering experiences influence illness and their impact on patients and families. Many professionals talk "around" suffering when interacting with suffering patients and families while failing to address its significance in their illness experience. Those professionals who do recognize its existence often struggle with how to offer supportive care while balancing suffering's toll on their personal and professional lives.

Conceptual frameworks for suffering encompassed a broad spectrum of views; major differences exist between practitioners who embraced the medical paradigm and nurses who are often grounded in the humanistic caring sciences. Cassell (1999) shared a commonly held definition for suffering based on the medical paradigm, "a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. It lasts until the threat is gone or integrity is restored" (pp. 531-532). The medical paradigm represents a perspective, labeled by Isovarra, Arman, and Rehnsfeldt (2006) as a "from-outside-approach" acknowledging how the medical framework relies on methods to measure or indicate status of illness rather than observations or comparisons of suffering. In contrast, a humanistic, caring paradigm, "from-inside-approach," emphasizes knowing the world of suffering patients based on their narrative or story (Isovarra et al., 2006, p. 248). Eriksson (2002) observed a trend toward more

integration of caring science knowledge in medical science which showed more interest in humanistic medical research, but recognizes different concepts were used by nurses.

Suffering is a key phenomenon impacting clients' decisions; and it is often not the basis for healthcare professionals' care and interventions. A critical need exists for all health care professionals to discover the significance of their clients' stories of suffering, and to unravel suffering's meaning and its impact on their patients' health care experiences, decisions, and healing process.

Conclusion

The discipline of nursing has such a significant and direct link to the care of patients and faces challenges related to embracing the realities of suffering in all care settings and with all types of patients. Despite the direct connection nurses share with suffering patients, there is an overwhelming lack of research on this topic in professional health care literature reflecting a lack of supportive research on the phenomenon of suffering in relation to the exploration of the deep meaning of suffering for patients and caregivers (White et al., 2004). The level of study completed in the United States doesn't appear to match the focus of multi-site scholarly qualitative studies occurring in Nordic countries that offer richer depictions of many dimensions of the phenomenon of suffering.

Suffering's toll on nurses is not disputed, but limited research and a general lack of awareness exists; there is a need for nurses to acknowledge their vulnerability and recognize their feelings as they encounter suffering (Eifred, 2003; Jezuit, 2000, 2003). Steeves, Kahn, and Beholiel (1990) depicted how the realization by nurses that they contributed to patients' suffering has caused some of them to leave nursing. Expanded

research on suffering can assist and support nurses as they care for their patients by enhancing their understanding of its impact on patients and themselves.

Assumptions

The investigation, grounded in relevant literature on suffering, began with the assumption that suffering is a universal yet highly individualized phenomenon. Persons will differ in their perspectives and identification of suffering in their lives, yet everyone will experience varying degrees and types of suffering events with consequential disruption in their lives.

Definition of Terms

The research design of this study was based on the exploration of distinguishing the phenomenon of suffering from the phenomenon of enduring. The life-impacting nature of suffering was recognized by Cassell (1991), “the severe distress associated with events that threaten the intactness of the person.” Others acknowledged how suffering encompassed many holistic components of afflictions that distinguished between two types of suffering: “physical and ‘the other,’” including other types of suffering as emotional, psychological, existential, metaphysical and spiritual (White et al., 2004). Rodgers and Cowles (1997) summarized suffering as an individualized, subjective, and complex experience characterized primarily by a person’s assigning to a situation or a perceived threat an intensely ‘negative’ meaning described by holistic traits.

Controversy existed related to distinguishing the concept of enduring as separate from suffering. Morse and Carter defined enduring as “the capacity to last;” “to get through” an extraordinary physical or psychological assault; or to survive an intolerable situation and remain intact (Morse & Carter, 1995, 1996). Many researchers, including

Frankl and Reich, viewed enduring as an integral component of suffering rather than a distinct concept, but Morse's pioneer work, the *Praxis Theory of Suffering*, defended how enduring is distinct from suffering (2001).

Supportive and compassionate nursing care was valued by patients (von Dietz & Orb, 2000). Empathy and sympathy were often viewed as synonymous with compassion, yet they were distinct terms with unique contributions for those who suffer. Clear distinctions between these caring terms were offered by von Dietz and Orb (2000). Empathy and sympathy share Greek derivations; empathy has both cognitive and affective dimensions and is often "viewed as the 'hook' into another person's emotions, often with an ulterior purpose or motive," and is "usually understood as enabling us to interpret the feelings, thoughts or perceptions of another person so as to provide professional care" (von Dietz & Orb, 2000, p. 167). Sympathy mimics the affective aspects of empathy, but is more passive in nature, much like pity; it is "defined as the capacity for being simultaneously affected with the same feeling as another" (p. 167). While empathy or sympathy are necessary components for therapeutic nursing intervention, they did not offer the active or engaged response desired in many suffering events. "Empathy implies being touched by and understanding the reality of another person, it does not specifically require action (von Dietz & Orb, 2000, p. 169). These authors demonstrated how nursing interactions based on empathic responses implied a level of observation or detachment from the patient.

In contrast, the concept of compassion, derived from Latin, means literally to "suffer with" (von Dietz & Orb, 2000, p. 168); and demands action. Compassion exceeds the feeling or expression of sympathy; it's the "active participation or experience of one

individual in another individual's suffering" (Graber & Mitcham, 2004, p. 87). Nouwen, McNeill, and Morrison (1982) expressed how compassion supports engagement and diminishes the boundaries of detachment that have often limited the connection of the professional with the suffering person in their description of compassion's dimensions:

Compassion asks us to go where it hurts, to enter into places of pain, to share its brokenness, fear, confusion, and anguish. Compassion challenges us to cry out with those in misery, to mourn with those who are lonely, to weep with those in tears. Compassion requires us to be weak with the weak, vulnerable with the vulnerable, and powerless with the powerless. Compassion means full immersion into the condition of being human (p. 4)

Compassion has moral dimensions and urges one to reach out to others beyond our own self-interests without being paternalistic; it is "not so much about what we choose to do *for* other people, but what we choose to do *together* with them" (von Dietz & Orb, 2000, p. 169). Finally, compassionate care is not "about taking away another person's pain or suffering, but is about entering that person's experience so as to share their burden in solidarity with them...enabling them to retain their independence and dignity" (von Dietz & Orb, 2000, p. 169).

In addition to a focus on the impact of compassion, the study also briefly explored perceptions of healing related to the suffering experience. Achterberg, Dossey, and Kolkmeier (1994) defined healing as "a process of embracing and transforming what we find most frightening or painful in our lives. It involves connection, unity, interdependence, and an openness to allow expansion of the human potential" (as cited by Smith, 2001, p. 22).

Significant critical attributes for healing encompass the following:

1. A sense of transcending the immediate environment or situation.
2. A sense of timeless connection, unity, and interdependence with the self and others.
3. A sense of inner knowing, strength and peace, even in the face of pain or suffering. The person has a sense of meaning and purpose in life. (Smith, 2001, p. 23).

Egnew's (2005) qualitative study on healing with seven allopathic physicians offered a comparison of healing definitions by several noted authors: "making whole again" (Cassell); "becoming whole again" (Kubler-Ross); and a spiritual experience (Stephens) (p. 257). Healing renews wholeness and is often spiritually-based.

CHAPTER II: LITERATURE REVIEW

Introduction

A growing intrigue with suffering has evolved in recent years, yet health care literature reflects a lack of supportive research on the phenomenon of suffering. The literature offers limited perspectives on the suffering of patients based on research; a single author's viewpoint is often presented rather than findings based on well-developed research studies, resulting in a poorly defined and undeveloped concept (Morse & Carter, 1996). While the closely related concept of enduring has been relatively ignored, suffering was often illustrated indirectly through narratives, yet lacks clarity in its definition. Nurses, known as the "caretakers of suffering" (Morse & Carter, 1996), tended to avoid the concept in most health care situations and patients rarely saw their plight or distress as suffering unless someone pointed it out to them (Cassell, 1991). The conceptual exploration of the concept of suffering, along with a review of the closely related concept of enduring, is the basis of this literature review.

Historical Perspectives

Conceptual frameworks for suffering encompassed a broad spectrum of views; major differences existed between practitioners who embraced the medical paradigm and nurses who are often grounded in the humanistic caring sciences. Cassell (1999) shared a commonly held definition for suffering based on the medical paradigm, "a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted. It lasts until the threat is gone or integrity is restored" (pp. 531-532). The medical paradigm represents a perspective, labeled by Isovarra et al. (2006) as a "from-outside-approach" acknowledging how the medical framework relies on methods to

measure or indicate status of illness rather than observations or comparisons of suffering. In contrast, a humanistic, caring paradigm, “from-inside-approach,” emphasized knowing the world of suffering patients based on their narrative or story (Isovarra et al., 2006, p. 248). Eriksson (2002) observed a trend toward more integration of caring science knowledge in medical science which showed more interest in humanistic medical research, but recognized different concepts were used by nurses.

Many historical perspectives of suffering failed to distinguish how suffering is different from pain, and many caregivers today continue to see insignificant differences between the two conditions. Significant earlier viewpoints related to the comparisons of pain and suffering, considered suffering as a secondary component of the pain experience (Beecher, 1957). Copp later recognized how some persons suffer in anticipation of pain rather than just in response to it (1974). A shift has occurred in recent years emphasizing that pain and suffering are distinct forms of distress, yet share some attributes (Cassell, 1991, 1994; Younger, 1995). More comprehensive conceptualizations are needed to consider how suffering is distinguished from the response of pain or psychological distress (Kahn & Steeves, 1986).

Theories that supported this study on suffering and enduring were grounded in caring human science theory based on the noted work by Leininger and Watson originating in the late 1970s through the present. However, the more recent work of two leading nursing science theorists, Swanson (1991, 1999) and Eriksson (1981 – present), offered caring theory with more nursing applications for those who suffer. Swanson’s practical *Middle Range Theory of Caring* built on Watson’s *Human Caring Theory* and described five caring processes and practices for caring action that showed evidence of

“the integration of caring-healing consciousness with nurse behaviors that support relationship-based care (RBC)” (Felgen, 2004, p. 293). Eriksson’s *Theory of Caritative Caring* (1990, 1995, 2003) stressed “the purpose of caring is and will remain linked to patients’ well-being and the alleviation of suffering based on the ethos of caritative caring science” (Eriksson, 2003 as cited by Lahdesmaki & Nyholm, 2007).

Conclusion

The phenomenon of suffering has been studied and conceptualized based on many theoretical perspectives and health disciplines. The diverse perspectives based on a medical paradigm, human caring theory, and nursing theory illustrate the phenomenon’s complexity and challenge for study. Due to the centrality of the suffering experience in healthcare and the diverse views regarding its meaning and impact on persons’ lives, further investigation and research is warranted to lead to the discovery of more effective and innovative supportive care for suffering clients and their families. There is a need for further understanding for the influence of suffering on nurses and all health professionals to explore how nurses can better respond to the toll that suffering demands from them personally and professionally.

Theoretical Context

Suffering

Conceptual frameworks and definitions for suffering have been varied, with distinct differences in perceptions by health disciplines, demonstrating historical patterns of confusion with pain and other closely related concepts. Cassell’s (1999) influence was reflected in many nurse researchers’ perspectives on suffering but a broader more holistic view has emerged in recent years. Kahn and Steeves (1986) acknowledged the

individual's threat to self and the meaning given to events such as pain or loss. Other nurses (White et al., 2004) distinguished between two types of suffering: "physical and 'the other'," including other types of suffering as emotional, psychological, existential, metaphysical and spiritual. Rodgers and Cowles (1997) conducted a thorough conceptual analysis of 56 articles exploring a wide range of dimensions of suffering, including attributes, antecedents, consequences, surrogate terms and related concepts. They summarized suffering as an individualized, subjective, and a complex experience characterized primarily by a person's assigning to a situation or a perceived threat an intensely 'negative' meaning described by holistic traits. Black and Rubenstein (Black, 2006; Black & Rubenstein, 2004) portrayed suffering as an issue of identity, "both bounded and unbounded," exhibiting a profound "sense of unreality," and viewing the suffering experience as "more than a sum of its parts" (p. S22-S23).

Morse and Carter's innovative research studies focused on how to recognize when persons are in the "enduring mode" of a difficult situation. When one endures, one is "extra-ordinarily present-oriented, intensely concentrating or focusing on things such as the hands of a clock, or breathing in and out" to grasp and fiercely maintain a sense of control (Morse & Carter, 1996, p. 48). Morse's ground-breaking work, the *Praxis Theory of Suffering*, defended how enduring is distinct from suffering (Morse, 2001). Rawnsley (1996) objected to the interpretation of enduring and suffering by Morse and Carter, while Younger (1995) equated both suffering and enduring, "to suffer also means to endure" (p. 55). Other researchers' studies lent support for depicting suffering and enduring as separate concepts with different characteristics and different experiences

(Duggleby,, 2000; Georges, 2002; Morse & Carter, 1996; & Sundin, Axelsson, Jansson, & Norberg, 2000).

Key components of Morse and Carter's (1996) portrayal of enduring included the "absence of emotion" or the intentional suppression of emotion to maintain control which can require all of one's energy reserves. Just as suffering is work, so is enduring. The sufferer fears the loss of control that may accompany a powerful emotional release. The overwhelming fear is that the sufferer may not be able to regain control and "hold it together" to last through a situation until they can safely seek emotional release in suffering (p. 48).

Caring Sciences

Theories that support this study on suffering and enduring are grounded in caring human science theory. Caring nursing practice is essential for any patient, but crucial for persons experiencing suffering; "caring is the essence of nursing and is the most central and unifying focus for nursing practice" (Watson, 1985 & 1999, p. 33). Two primary nurse theorists in caring science from the United States who have shared noted contributions to establish and further caring human science theories included Leininger (1981) and Watson (1979, 1985, 1999, 2002, 2005). Smith (1999) and Swanson (1999) have also made recent caring science contributions while several notable nurse theorists from Scandinavia have also contributed significant influence in advancing caring science theory including Eriksson (1990, 1995, 1997, 2003).

Leininger's early contributions and leadership in organizing the first three national caring conferences in the United States in 1978, 1979, and 1980, are summarized in her text, *Caring: An essential human need* (1981). Leininger's presentation at the first

national caring conference in 1978 raised concerns for an anthropological approach for the study of care and caring; recognized the ambiguities about caring and the many unanswered questions related to caring; and expressed rationale for the study of caring. Leininger referenced Mayeroff's (1971) work on caring; she defined care or caring as "those assistive, supportive, or facilitative acts toward or for another individual or group with evident or anticipated needs to ameliorate or improve a human condition or lifeway" (Leininger, 1981, p. 9). Leininger (1981) distinguished professional caring from caring as "those cognitive and culturally learned action behaviors, techniques, processes, or patterns that enable (or help) an individual, family, or community to improve or maintain a favorably healthy condition or lifeway" (p. 9). Leininger's distinction between care and cure, which offered relevance for the study of suffering, were included in her assumptions and beliefs: "there can be no curing without caring; but there may be caring without curing" (1981, p. 11).

Watson also shared a presentation at the first National Caring Conference (1978) titled, "Some issues related to a science of caring for nursing practice." Watson's long-term and widely accepted contributions in caring human science have evolved through several decades from her early work in the late 1970's through the 1990's of her *Transpersonal Caring Theory* (1979, 1985, 1999, 2002, 2005). Watson's (1985) early

definition of caring also referenced Mayeroff's (1971) views on caring:

We sometimes speak as if caring did not require knowledge, as if caring for someone, for example, were simply a matter of good intentions or warm regard...To care for someone, I must know many things, I must know, for example, who the other is, what his powers and limitations are, what his needs are, and what is conducive to his growth; I must know how to respond to his needs and what my own powers and limitations are. Such knowledge is both general and specific (p. 13).

Watson defined human caring in nursing as the moral ideal that is “not just an emotion, concern, attitude, or benevolent desire...involves values, a will and a commitment to care, knowledge, caring actions, and consequences” (1985 & 1999, p. 29). Watson offered a list of more definitive caring interventions in her list of ten “carative factors,” implemented in current caring practices:

1. Humanistic-altruistic system of values
2. Faith-hope
3. Sensitivity to self and others
4. Helping-trusting, human care relationship
5. Expressing positive and negative feelings
6. Creative problem-solving caring process
7. Transpersonal teaching-learning
8. Supportive, protective, and/or corrective mental, physical, societal, and spiritual environment
9. Human needs assistance
10. Existential-phenomenological-spiritual forces (1985, p. 75)

Watson (2005) supported the continued relevance of these “10 carative factors,” as not only a framework for nursing, but also extended these factors to all health and healing professions. The evolution of her *Transpersonal Caring Theory* extended these “timeless and enduring” carative factors as the core for professional practice and offered a more explicit relationship between caring and love.

Watson's caring theory emphasized how ontological caring competencies and technological medical competencies evolved from the foundational caring relationship.

The nature of suffering involved connecting caring aspects of healing with the technical medical treatments that led to a cure or some measure of relief from suffering. Watson (2005) moved toward the term, “Caritas,” closely related to the original “carative” term, which emphasized “a deep form of transpersonal caring and love to come into play as part of the caring-healing perspective guiding Caring Science today” (p. 3).

Watson (2002) and Smith (1999) summarized recent developments that have advanced the affirmation of caring science in nursing including three specific areas of expressions of caring: “manifesting intention, appreciating pattern, and attuning to dynamic flow (Watson, 2005 pp. 12-13). Selected evidence that demonstrated progress in the development and establishment of caring theory and science included the existence of academic nursing departments in Nordic countries named, “Caring Science;” two international journals in nursing on caring; twelve years of “Caring Science” research publications (through the University of California, San Francisco for 12 years); and the establishment of the International Professional Nursing Organization International Association of Human Caring (IAHC) which is over twenty years old (Watson, 2002). Curriculum standards that recognized caring as a core concept in nursing have also been established by professional nurse organizations including the American Nurses Association (ANA) and the National League for Nursing (NLN). Watson (2005) nurtured the development of continued research on caring and measurements of caring outcomes by compiling a collection of tools to measure caring to facilitate and enhance further research of the phenomenon of caring.

Leininger’s and Watson’s ongoing research in caring science theory influenced many other theorists and established a reference point for analysis and comparisons of

other theorists in this field. Swanson offered significant empirical and theoretical contributions leading to the development of a *Middle-range Theory of Caring* based on her definition of caring as [“a nurturing way of relating to a valued other towards whom one feels a personal sense of commitment and responsibility”] (Watson, 2005, p. 13). She defined five processes whereby caring is manifested in her theoretical framework; and demonstrated applications for those who suffer:

1. Knowing – striving to understand an event as it has meaning in the life of Other
2. Being with – being emotionally present and available
3. Doing for – doing for other what they would do for themselves if at all possible.
4. Enabling-facilitating the Other’s passage through life events and transitions by providing information, validation, and support
5. Maintaining belief-sustaining faith in the capacity of the Other to get through events or transitions and face a future with meaning. (Watson, 2005, pp. 13-14)

Swanson’s classic meta-analysis research study of 130 empirical nursing research studies offered further support for the relevance of caring theory. Her meta-analysis research findings offered consequences of caring and non-caring for both patients and nurses (1999).

Nursing Sciences

Eriksson’s contributions to caring science research (1990, 1994 as cited by Lindholm, Holmberg, & Makela, 2005) linked caring theory with suffering nursing theory as she offered her *Theory of Caritative Caring* with a focus on health and suffering, based on extensive caring research in Nordic countries. Eriksson’s caring theory stressed the ontological core of caring with two conceptions of caring including compassion and human love, known as the *caritas* motive, or the basic motive of caring

(Eriksson, 2002; Arman & Rehnsfeldt, 2006). Her theory emphasized the alleviation of suffering and preservation of life and health and her axiom of health defined “health as more than the absence of illness and that health implies being whole in body, soul, and spirit. The substance of health has been summed up in a thesis in which she described health as movement in becoming, being and doing; striving for wholeness and holiness” (Lindholm et al., 2005, p. 34).

Eriksson (2002) showed health and suffering belong together as two sides of the same movement.

Starting from the *caritas* motive, compassion for a fellow human being arises in meeting a suffering human being. Suffering can be alleviated in a relationship characterized by responsibility and a desire to do good. All caring is formed in the relationship between patient and caregiver. In this relationship, the patient is seen as a unique human being, an entity of body, soul, and spirit. This spiritual dimension is stressed as spiritually existential, spiritually religious, and spiritually Christian. (p. 63)

Lindholm et al. (2005) showed that Eriksson viewed human vitality as the basic and inmost substance of health; it “comprises human strength for delight, strength for desire, strength for wishing and longing, will-power and energy, as well as the strength and power to live and bear one’s life” (p. 34).

Healing

The study will include a brief exploration of perceptions of healing related to the suffering experience. Healing is an ambiguous phenomenon to define, but Smith (2001) offered critical attributes for healing based on a concept analysis of healing in chronic pain. Smith (2001) related how Webster’s New World Dictionary (1995) and Tabor’s Medical Dictionary (1997) view healing in a limited physical sense and interchange it with curing, but Burton (1992) shared a view of healing as not just a change in

circumstances or problem, but a change in one's perception of the difficulty (as cited by Smith, 2001, p. 22). Smith reflected that "it is possible to be cured yet not healed, and to experience healing without being cured" (p. 22). Achterberg, Dossey, and Kolkmeier (1994) defined healing as "a process of embracing and transforming what we find most frightening or painful in our lives. It involves connection, unity, interdependence, and an openness to allow expansion of the human potential (as cited by Smith, 2001, p. 22).

Significant critical attributes for healing encompassed the following:

1. A sense of transcending the immediate environment or situation.
2. A sense of timeless connection, unity, and interdependence with the self and others.
3. A sense of inner knowing, strength and peace, even in the face of pain or suffering. The person has a sense of meaning and purpose in life. (Smith, 2001, p. 23).

Caring theorists within the caring/healing framework viewed the "healing relationship as better understood as being more than and different from the sum of its parts" (Quinn, Smith, Rittenbaugh, Swanson, & Watson, 2003). Egnew's (2005) qualitative study on healing with seven allopathic physicians offered a comparison of healing definitions by several noted authors: "making whole again" (Cassell); "becoming whole again" (Kubler-Ross); and a spiritual experience (Stephens) (p. 257).

Suffering and Enduring

Examples and Sources of Suffering

Examples of suffering reveal the sources or etiologies of suffering. Physical etiologies, such as unrelieved pain, commonly underlie suffering, but other causes include the death or suffering of a loved one; a sense of powerlessness, helplessness, or hopelessness; the loss of a life's work; deep betrayal or isolation; memory failure; or

unremitting fear (Morse & Carter, 1996, p. 46). Another source of suffering, grief or chronic sorrow, can be confused with suffering; yet it's a source or type of suffering. Chronic sorrow, or prolonged sorrow, is a response to an ever present loss situation that mimics the cyclic nature of suffering as sadness recurs with its intensity ebbing and flowing, with no predictable end (Melvin & Heater, 2004). Additional causes or examples included the loss of self; impaired body image; facing mortality and end-of-life issues; unresolved family dynamics; loss of meaning; discontent with one's situation; a general feeling of loss; and unfulfilled hopes or aspirations (White et al., p. 440). Georges (2004) related how a broader, population-based perspective of suffering may impact many vulnerable persons in society through social suffering, resulting from the impact of political, economic, and institutional power on people. Suffering issues are unique for different age groups, but limited research exists to support how persons of different ages suffer. Black and Rubenstein's (2004) study with elderly persons found distinct issues in suffering related to the quality and meaning in elders' concerns that their unique voices will soon be silent, reflecting how issues of suffering are ultimately issues of identity.

One alarming source of suffering for patients seeking healthcare includes suffering caused by healthcare professionals, such as nurses (Arman, Rehnsfeldt, Lindholm, Hamrin, & Eriksson, 2004). Suffering can result due to care by others as one's dignity and personhood is violated; through condemnation or punishment; assertion of power; or omitted care or non-caring (Jonas-Simpson, 2007). This issue has widened the gap in building trusting relationships between patients and caregivers, further diminishing rewarding encounters for caregivers in their work. Cutcliffe (2006b) stressed the importance for caregivers to distinguish between "causing a person pain and facilitating a

person in accessing his or her pain that *already exists*” (p. 604-605). Caregivers who recognized how they inflicted or deepened another person’s suffering shared stories of their own suffering as the “healer,” which drove them away from their nursing profession unless they received recognition and support from others (Rowe, 2003).

Suffering Characteristics and Manifestations

Suffering is highly individualized for each person, and presents challenges for assessment and recognition in others. One distinctive trait relates to its hidden nature, even from sufferers who may not be aware that their distress is indeed suffering and who may need to be asked to confirm its presence (Cassell, 1991; Kahn & Steeves, 1995). This subtle quality impacts how difficult it can be to recognize suffering, since a patient may not be able to tell one it exists. “It’s what your patients can’t say...suffering is the unspeakable...it is what remains concealed, impossible to reveal; it remains in the darkness, eluding illumination; and it is dread, beyond what is tangible even if hurtful” (Frank, 2001, pp. 354-355). Isovaara et al. (2006) examined this hidden quality of suffering with a family experiencing suffering related to war experiences and found that “the deepest truth about the concept of suffering is hidden inside the one who is suffering” (p. 248).

Another phenomenological study of stroke survivors’ experiences by Murray and Harrison (2004) also confirmed the invisibility of their emotional difficulties and the lack of understanding by others; these survivors yearned for a more visible disability which they thought would attract more empathy and understanding from others. Raholm and Eriksson (2001) contrasted visible, explicit suffering with concealed and unrevealed suffering, and Younger depicted how this unrecognized suffering alienated one from

others, caused by the inability to communicate the impact of suffering with ones' voice (1995). Younger (1995) showed how recovery from suffering is promoted through expressing one's story and finding an "autonomous and authentic" voice to make suffering known to others.

Specific manifestations or behaviors commonly exhibited by those who overtly express their suffering include an overwhelming emotional response or a grief-stricken emotional expression such as weeping, wailing, howling, or crying; and feelings of anguish, fear, panic, worry, guilt, anger, anguish, depression, sorrow, or loss of control (Morse & Carter, 1996, p. 49). Constant crying or "a wave of overwhelming sadness may sweep over the individual" (Morse & Carter, 1996, p. 52). Rehnsfeldt and Eriksson (2004) studied written narratives of persons who suffered breast cancer along with some of their significant others and recognized a significant "turning point" for these sufferers between unbearable and bearable suffering. This "turning point" was marked by an acute need to express oneself, to gain communion with others.

Morse (2000) studied the "cues of suffering" and reported that the "signals of distress," nonverbal or verbal expressions, were evident to others and prompted others to offer comfort. Morse's interaction research supported how caregivers' responses "follow each signal of distress instantaneously." For instance, in "trauma care, if a person cries out in pain, the nurse interrupts the cry with a 'there, there', a 'Shhhshh,' or 'we're nearly done'" (Morse, 2000, p. 5). These unconcealed expressions of suffering prompted others to care, show pity, express empathy, offer condolences, listen, hold, or touch the sufferer (Morse, 2000).

Emergence of “Enduring” As Distinct from Suffering

A minority of researchers supported the concept or social process of enduring as an emerging and distinct concept from suffering. Morse and Carter are two primary researchers who conducted several extensive qualitative studies on suffering lending support for this distinct concept of enduring (Morse, 1997, 2000, & 2001; Morse & Carter, 1995 & 1996). They defined enduring as “the capacity to last;” “to get through” an extraordinary physical or psychological assault; or to survive an intolerable situation and remain intact (Morse & Carter, 1995; 1995). Many researchers, including Frankl and Reich, viewed enduring as an integral component of suffering rather than a distinct concept, but Morse’s pioneering work, the *Praxis Theory of Suffering*, defended how enduring is distinct from suffering (Morse, 2001). Rawnsley (1996) objected to the interpretation of enduring and suffering by Morse and Carter, while Younger (1995) equated both suffering and enduring, “to suffer also means to endure” (p. 55). Other researchers’ studies lent support that suffering and enduring are separate concepts with different characteristics and different experiences (Duggleby, 2000; Georges, 2002; Morse & Carter, 1996; & Sundin et al., 2000). The findings of Duggleby’s grounded theory study with eleven elderly hospice patients with cancer revealed how enduring is a basic social process, a “conscious active process that required strength, willpower, and work” (p. 827).

Characteristics and Manifestations of Enduring

Some primary researchers who explored facets of enduring included Arman, Rehnsfeldt, Lindholm, & Hamrin (2002); Georges (2002); Morse (1997, 2000, & 2001); Morse and Carter (1995 & 1996); Sundin et al. (2000); and Younger (1995). Morse and

Carter's pioneering research studies focused on how to recognize when persons are in the "enduring mode" of a difficult situation. When one endures, one is "extra-ordinarily present-oriented, intensely concentrating or focusing on things such as the hands of a clock, or breathing in and out" to grasp and fiercely maintain a sense of control (Morse & Carter, 1996, p. 48). Key components of Morse and Carter's (1996) portrayal of enduring included the "absence of emotion" or the intentional suppression of emotion to maintain control which required all of one's energy reserves. Just as suffering was work, so was enduring. The sufferer feared the loss of control that may accompany a powerful emotional release. The overwhelming fear was that the sufferer may not be able to regain control and 'hold it together' to last through a situation until they can safely seek emotional release in suffering (p. 48).

Distinct manifestations of enduring are unique from suffering – the endurer blocks emotional expression through various types and levels of suppression – all dependent on the intensity or severity of the threat (Morse, 2000). In its most extreme level of enduring, the person appears emotionless, moving in chunky movements, walking with a robot-like gait, stiff and erect (Morse, 2000). Morse's study of "cues of suffering" indicated persons who endure have limited nonverbal and verbal expressions in short sentences, and persons may speak in a monotone voice with dull, unfocused eyes. The primary focus is the present which helps to keep them going and limits the past and future's power over you. Coping with suppression of emotions is a struggle, and people may erupt in anger at unrelated events or encounters. Morse and Carter (1996) recognized that behavioral manifestations of enduring tended to make others withdraw and be less likely to touch or hold the enduring person, limiting support and comfort in this state.

Morse and Carter (1995) recognized significant phases of recovery for enduring and suffering through their ground-breaking case study research study with a woman, Joan, who suffered exceptional losses including life-threatening burns in a house fire that eventually led to the death of all of her three children. Her husband divorced her during her recovery following an extramarital affair. Joan's journey of suffering revealed four phases of recovery: enduring to survive, enduring to live, suffering, and reformulation of self. During the phase of *enduring to survive*, the burn victim, Joan, found that enduring required so much of her inner resources, her concentration, and energy that suffering was absent. This phase of suffering to survive and "live through the agony" required a complete focus on the present, even minute by minute. The transition to the second phase, *enduring to live*, involved self-protection and refusal to face reality. A wall was built by Joan to shut out suffering as she refused to survey or look at the damage from her burns on her body and avoided others' gazes while living vicariously through others (Morse & Carter, 1995). The steps for readiness to confront or face suffering involved gathering enough energy to accept the "emotional force of suffering," resulting in a greater risk for suicide. Morse and Carter (1995) noted the all-consuming work of suffering needed to work through the event that required Joan to relive her horrors again and again, rediscovering events until they were accepted as something that really happened, and attained resolution through discovering a value on the experience and one's own behavior. The outcome of this extensive suffering phase, when one has suffered enough, was the reformulated self; a person who was different, wiser, more empathic and blessed with a deeper appreciation of life and others.

Morse and Carter's (1996) broader second research study of enduring and suffering followed with 27 post-discharge interviews with patients and relatives six months after they experienced traumatic injuries, burns, chronic illness, major surgery, AIDS, and bereavement. This 1996 study helped Morse and Carter refine the types of enduring and established one more step in enduring – *enduring to die*. These steps of enduring; *enduring to survive*, a physiological endurance; *enduring to live*, a psychological endurance; and *enduring to die*, both physiological and psychological; were present in terminal patients (Morse & Carter, 1996). *Enduring to survive* occurred in response to an extraordinary physiological threat, where the victim needed to hold on through overwhelming pain, injury, or excruciating treatment. *Enduring to live*, occurred when the individual faced psychological threat with life experiences that present “no apparent alternatives, no reprieve, or no release.” When a person has a recognized terminal illness where the individual and/or family desire the pain and suffering to end, the focus of *enduring to die* helped the person “hold on” to finish business and closure with one's life.

Additional studies by other researchers lent support for the significance of the concept of enduring. Morse, Bottorf, and Hutchinson (1994) studied comfort interventions for nine conditions of the body including the “enduring body.” They described how patients were forced to endure with no alternative or choice, and described how comfort measures were needed to focus on supporting the patient's ability to refocus their attention to gain strength to endure in the present. Sundin et al. (2000) conducted a phenomenological hermeneutic study with four hospitalized men and six women, based on Eriksson and Younger's perspectives on suffering, revealing four themes in the

patients' suffering experience: (a) having a good rest, (b) suffering through, (c) searching for autonomy, and (d) being cared for by attentive and committed staff. The first theme, "having a good rest," was comparable to the enduring phase with observed patient behaviors including a passive state, not wanting to be left alone, leaving responsibility to staff, resting, and wanting to think things through. The second theme, "suffering through" more closely matched the expression of suffering with the need for consolation and venting of feelings related to one's predicament. An extensive research project in Sweden and Finland with 49 interviews with cancer patients and their significant others, by Arman et al. (2002) identified two themes demonstrating similarities with enduring: a "doubled suffering" which remains concealed or unspoken; and "enduring surrounding and relief from suffering." Lohne's (2005) longitudinal qualitative study with ten persons who suffered spinal cord injuries revealed findings that experiences of hope and hoping within critical care nursing have been associated with fostering individual endurance and hopes of personal improvements. Lohne's findings revealed two themes, "the vicious circle" and "longing," revealing the long road of recovery with repetition, ups and downs, and a search for renewed meaning.

Duggleby's (2000) grounded theory analysis of the pain experience of eleven elderly hospice patients with cancer supported the process of enduring as a basic social process, a "conscious, active process that required strength, willpower, and work" (p. 827). Participants described enduring as "living with" and "bearing" the pain as well as "holding up" and "not giving in" to the pain. The cancer patients described "not enduring" as "giving up," "going into oblivion," or "not caring about anything." Duggleby (2000) identified two sub-processes of enduring: (a) "maintaining hope,"

important to endure suffering to overcome suffering, and hope or trust in a higher being to gain peace and assurance; and (b) “adjusting” to pain to last longer with cancer.”

Adjusting involved dealing with uncertainty and accepting and minimizing pain; and the enduring person gained strength through faith and encouragement from family to “adjust” to pain. Duggleby emphasized the lack of research on these particular sub-processes of enduring that had not been reported as a “basic social process” in previous grounded theory studies of pain.

The Cycle of Suffering and Enduring

Few studies reported how persons actually transition between suffering and enduring. While many researchers supported how individualized the process of suffering was for each patient; Morse and Carter’s research, based on extensive interviews with 27 patients who incurred burns, major trauma, chronic illness, and major surgery, was designed to track the process of enduring and suffering. Their model, “The Cyclical Relationship between Enduring and Suffering” (Morse & Carter, 1996, p. 53), depicted the significance of the interconnectedness between suffering and enduring. The emotional components of each state were primary characteristics that differentiated suffering and enduring. The person moved back and forth between suffering and enduring, reliving the experiences or threats and hoping to share their suffering story with anyone who would listen. During the enduring phase the individual conserved energy through emotional suppression, gaining enough strength to acknowledge what had been endured, and was able to move into the work of suffering and more observable emotional expression. When the work and pain of suffering has depleted the individual’s energy and drained their emotions, the person moved back to the enduring state to conserve energy (Morse &

Carter, 1995 & 1996). This process continued until the person had recovered or the threat was gone.

Outcomes of Suffering and Enduring

According to Morse and Carter (1995), acceptance moved the individual from suffering to a “reformulation of the self.” Persons recognized that they were different persons, having survived what they had suffered and endured. Successful enduring was crucial to help ease the burdens on family imposed by suffering; enduring the pain was valuable for finding peace and maintaining dignity and relationships with others. One person interviewed by Duggleby (2000) reported, “I’m able to act decently, peaceful, just everything to get along with the family and for the family to get along with me” (p. 827). Many persons experienced a sense of renewal, meaning and joy, and a new perspective on values and priorities about life and living. Individuals found special strength and empathy for others with an ability to recognize the inner beauty of a person, special bonds with family, and a sense of purpose (Morse & Carter, 1995). Some persons were able to reach out to help others who were in the midst of suffering and enduring based on their unique suffering experiences. For most persons this transition toward acceptance and reformulation was a gradual process, with some days still lived in a suffering state.

Wayman and Gaydos (2005) related how suffering is a “wake-up call” and an invitation to change; resulting from taking time to pause, to be emptied of the pain, to confront or acknowledge suffering, and surrender. Other significant outcomes reported by Wayman and Gaydos’ (2005) research yielded many themes related to the self-transcendence of suffering, based on interviews with two men and two women who suffered a variety of life-impacting suffering events. The persons’ narratives related

extraordinary experiences about change and a renewed value of life; who became more aware of who they really were; and found meaningful work that achieved more congruence between their personal and professional lives. They reported a sense of gratitude for the “treasures” of suffering and humility for the “gifts” of suffering.

Spirituality and a quest for meaning and purpose are at the core of the whole experience for many who suffer and endure. Raholm and Eriksson (2001) acknowledged the way to spirituality is through suffering and desire. Outcomes achieved a new wholeness (Fredricksson & Eriksson, 2001) and facilitated the release of painful emotions, removing the ‘emotional lodestone’ that often trapped clients in hopelessness and brought relief and lightness to their spirit (Cutcliffe, 2006b). Gunderman (2002) summarized the significance of meaning in suffering, “it’s not suffering that destroys people, but suffering without meaning” (p. 43). In a qualitative ethnographic study with people enduring mental disorders, Adam, Tilley, and Pollock (2003) reflected how people saw themselves holistically, not as separate from their mental health problems but rather “as more than, and living a life not reducible to, mental health problems or illness” (p. 210).

Supplemental Theoretical Context

Supportive Care for Those Who Suffer and Endure

Many studies have uncovered the great significance of “good” and “not so good” care gained by listening carefully to those who suffer (Attree, 2001). In the “drama of suffering,” Lindstrom, Lindholm, and Zetterlund (2006) shared a critique of Eriksson’s mid-range theory of caring for suffering, recognizing the goal is reconciliation with suffering for each suffering participant and their significant others. Due to the individual

nature of each person's lived experience with suffering, many researchers supported how nursing care must be "sufferer-led," with interventions guided by the voices of those who have lived suffering (Eriksson, 1997; Georges, 2002; Melvin & Heater, 2004; Morse, 2000, 2001; & Sundin et al., 2000). Melvin and Heater (2004) illustrated how entering into the suffering experience of another was like "entering into a dance with the person...nurses rely on the movement of the client to tell us what it is" (p. 45). Patients who suffered needed to be seen as "directors of their own drama" (Sundin et al., 2000). Comforting interventions responded to the "cues of distress" from those in need of comfort (Morse, 2000).

The degree and timing of confrontation of emotions and the suffering experience itself is a controversial point in supportive care. A risk exists to prematurely encourage patients to express their emotions and details of their experience in suffering, especially if that person who suffers is enduring and working to avoid expression. Morse and Carter (1996) warned of the need to foster endurance and avoid premature expressions of suffering that can be damaging for the sufferer; they encouraged further research in supportive care for those who endure.

Another issue for enhancing supportive care for those who endure is identifying crucial persons who help the critically injured regain a sense of reality from the nightmares of trauma. Many hospital visiting policies actually blocked or limited the availability of supportive persons in critical care areas (Morse & Carter, 1995). Wayman and Gaydos (2005) stated that not all nursing researchers advocated surrendering to suffering by confronting the reality of suffering to move beyond suffering, but in their study they found surrendering to suffering to be essential to healing, by accepting what

could not be changed. Rehnfeldt and Eriksson (2004) conceived how unbearable suffering required confrontation and one shouldn't fear asking questions that persons asked themselves. Cutcliffe (2006b) agreed on the importance of the recognition of the "fundamental difference between causing a person pain and facilitating a person in accessing his or her pain that *already exists*." (p. 604-605). Cutcliffe (2006a) emphasized the significance of "unwavering commitment" for the sufferer who tested their safety in the care giving relationship by showing a glimpse of their pain, intensity of emotion, or the horror of their situation with the caregiver. The caregiver needed to demonstrate their tolerance and acceptance with the patient by not abandoning them or ignoring them.

Suffering and enduring was "work" (Duggleby, 2000) that placed high demands for holistic individualized caring acts from all caregivers (Arman & Rehnfeldt, 2007). Essential key traits and skills that caregivers needed to offer holistic care for those who suffered included but were not limited to presence, courage, comfort, and the anticipation of needs. Presence was critical for fully offering oneself through "being vs. doing" to decrease the sufferer's sense of isolation and give them opportunities to share their stories of suffering (Katz & Johnson, 2006). Courage was a key component for caregivers to exhibit in their caring, since one has to be "brave enough to face suffering, to walk straight up to or right through it" (Lindholm & Eriksson, 1993, p. 1360). Many nurse researchers have studied comfort, but a distinctive language of comfort offered encouraging words that supported persons who suffered and endured, attuned to the subtle verbal and nonverbal cues from that person in the moment of a painful episode or procedure (Morse, 1997; Morse, Bottorf, & Hutchinson, 1994). Nurses offered support through direct and indirect comforting strategies that supported patients' ability to learn

self-comforting interventions (Morse, 1997). Finally, a major study based on mixed qualitative and quantitative methods to explore clients' expectations for care noted the significance of "anticipated needs" which communicated concern, care, and an appreciation for person's individual needs and personhood (Redman & Lynn, 2005).

Non-supportive Care for Those Who Suffer and Endure

Patients' narratives or stories of their suffering and enduring guide the choice of effective interventions and also reveal what isn't supportive in their care. Nurses can learn "what not to do" to avoid inflicting further pain and delays in the promotion of healing for the suffering person. Patients endure even further suffering through non-supportive care including assaults on their sense of dignity and personhood, through avoidance as they suffer and endure, and through ineffective communication. Many researchers recognized the overwhelming impact of depersonalization and deprivation of dignity for those who suffer (Eriksson, 1997; Owens, 2005; & Rawnsley, 1996). Patients were not seen as persons, and in that loss of personhood or disembodiment was the loss of dignity and support for the individualized experience of suffering and enduring (Owens, 2005).

Avoidance of persons who suffer and endure was common; caregivers focused on tasks or "talked around" the key issues of suffering due to the caregiver's sense of vulnerability and struggle to be authentic with patients (Eifred, 2003). Avoidance was commonly unintentional, resulting from the witnessing of multiple encounters with overwhelming loss, suffering and threats to the same person or groups of persons on a constant basis. Wiman and Wikblad (2004) conducted a study of caring in the emergency room, videotaping five care episodes. These episodes revealed that uncaring is more

common than aspects of caring. Uncaring actions were depicted as a wall with three basic components: incompetence and indifference; lack of trust, and mutual avoidance and disconnection between the nurse and the patient (p. 424). “Medicalization or pharmacologic muting” of suffering symptoms and behaviors was another example of avoidance (Morse, 2000).

Ineffective communication is one final non-supportive category of care which is quite controversial. Morse, Bottorf, Anderson, O’Brien, and Solberg (2006) disputed the long held practices of what is termed, “therapeutic empathy” used to comfort those who suffer. They saw a need to explore alternative communication methods that fully supported strategies for nurses to truly experience patients’ view of suffering from the patient perspective rather than the nurse’s perspective. Diverse views existed regarding the effectiveness of supportive communication methods with suffering individuals. Rawnsley (1996) disagreed with nurses who encouraged individuals to express suffering since this violated the “do no harm” ethic – rather efforts needed to be made to restrict it and eliminate it. These views present many implications for determining best practices in the supportive care of suffering individuals.

Impact of Suffering on Nurses

Suffering’s toll on nurses is not disputed, but limited research has been done in this area. A general lack of awareness existed and there was a need for nurses to acknowledge their vulnerability and recognize their feelings as they encountered suffering (Eifred, 2003; Jezuit, 2000, 2003). Steeves et al. (1990) depicted how the realization by nurses that they contribute to patients’ suffering has caused some of them to leave nursing. Maeve (1998) conducted a descriptive phenomenology study with nine

nurses to determine how nurses live with the suffering and the dying. The findings of Maeve's study revealed three themes for coping: (a) tempering involvement, such as setting limits and boundaries, coming to love or not love a patient; (b) doing the right thing/the good thing, involving competency, commitment, and courage; and (c) cleaning up, literally to soothe ones' sense of loss and grief with dying patients and a need to self-review in difficult patient encounters. Several researchers implied that nurse engagement was more rewarding for nurses who experienced a reciprocal exchange with patients and this engagement reduced the risk for nurse or caregiver burnout (Morse et al., 1996).

Nurses recovered from their encounters with patients who suffered through peer support, supervisor care and support, and education. Soderberg, Gilje, and Norberg (1996) observed in their study in six regional hospitals in intensive care units that nurses were reluctant to share strong emotions between staff, limiting the acknowledgement of one's own vulnerability as well as respecting the vulnerability of peers. Zuzelo (2007) conducted a large mixed methods study with 100 nurses to determine what were the most distressing moral events encountered by registered nurses (RNs) and how frequently they were experienced in practice. The quantitative findings of this study identified the three most distressing events (out of 23 listed): working with nurses one considered to be unsafe, working with nurses who were not as competent as the patient care requires, and following orders for ineffective pain medications. Qualitative findings revealed the following themes: resenting physicians' reluctance to address death and dying, feeling frustrated with a subordinate role, confronting physicians, ignoring patients' wishes, feeling frustrated with family members, treating patients as experiments, and working with staffing perceived as inadequate. None of these themes recognized the stress of

suffering, but some themes related concern for unmet patient needs and loss of personhood.

The recommendations of the study by Zuzelo (2007) supported the need for better education for nurse managers to deal with ethical dilemmas and support for nurses, need for ethical rounds, discussion groups, and debriefing sessions. Steeves et al. (1990) recognized the need to study additional work stressors, in order to avoid losing valuable staff or to contribute to the avoidance and distancing of staff from patients who suffered and their families. White et al. (2004) proposed the need for strategies to alleviate the personal impact of suffering with more support from work colleagues and personal support from family and friends to offer the recognition and support for nurses who suffered along with the patients they serve.

Summary

In conclusion, the implications of what is known about suffering should be impacting significant changes in practice, but there was very limited research that addressed “best practices” for those who suffer. Due to the lack of study in this field related to health care practices, there is a disturbing need for concern and respect for the personhood and dignity of those who suffer in healthcare situations. Studies revealed that institutional practices and policies failed to ensure the support suffering individuals deserve, and often further contributed to the suffering experience of persons, who were already “living suffering.” Further disregard was evident for the healthcare personnel, including nurses, who experienced the emotional, physical, and spiritual toll due to direct care with persons who suffered. These trends will continue unless educational and supervisory approaches are developed and implemented to address the unique needs of

patients and staff. Studies indicated that technological advances and the caregiver's tasks linked to the delivery of high-tech care, continued to dominate health care and limited the desire and capacity to offer a personal human connection with suffering individuals. Learning to recognize suffering required a shift away from a virtually exclusive concern with the body and disease toward a primary concern with the sick person, including the body and its diseases (Cassell, 1991).

The need for further study was present in all facets of this literature review. Fredriksson (1998) suggested the extent of this need for change for care of the suffering individual in her term, the "chaos of caring." A need exists for the education of students and healthcare personnel to enhance their recognition and assessment skills for the patient who is either suffering or enduring based on a threat or overwhelming crisis. This requires more research on patients' narratives of suffering needed for acquiring more information about the lived experiences of individuals who suffer, which could also have relevance for addressing all topics of health in conversations. A strong educational emphasis is needed to develop best practices for supportive care which is "sufferer-led," to enhance healing and the alleviation of suffering. The influence of cultural aspects, age, gender, and population traits on suffering requires further study. Healthcare specialty areas must consider unique adaptations for offering more personalized care for patients that suffer in their hospital units or care settings. Finally, extensive review of the impact of suffering on all caregivers is critical to support nurses' retention, their ability to be present for those who suffer, and for their own self-renewal.

CHAPTER THREE

METHODOLOGY

Research Design

This qualitative study followed an interpretive phenomenologic approach to answer the grand tour question: What is the lived experience of persons who have endured life-impacting suffering events? An examination of adult participants' diverse suffering experiences was based on their deep reflection of descriptions of their suffering journey compared with their experiences of enduring. Additional reflective exploration included the impact of suffering on one's life, significant support received from others, support that was desired but neglected, perceptions of healing in suffering, and self-discovery gained through suffering.

This extended study followed a brief pilot study completed during 2007 with a colleague partner.

Identification of Sample

The purposive, intensive sampling design included eight participants who exhibited maximum variation, while limiting deviant case sampling. Diverse adult participants of various ages, ethnic backgrounds and gender were recruited through professional contacts using the snowball technique to identify persons who were at all stages in their suffering experience. Attempts were made to avoid interviewing persons during hospitalizations, times of extreme crises or disruption in their lives; thus making several potential participants, particularly several who were 40 or under, and who represented additional minority groups, unavailable for the study.

Ethical Considerations

The amended study proposal was approved by the College of Saint Mary Institutional Review Board (IRB) on March 23, 2008. The original pilot study received initial approval from the College of Saint Mary Institutional Review Board on February 26, 2007, and was classified as exempt (approval number CSM 07-014). The related documentation is available in Appendix B. The researcher's required training in human subjects research was completed prior to approval from the College of Saint Mary IRB. Consent forms were completed by all participants prior to each interview, the risks and benefits for participation in the study were shared for all participants, and the availability of counseling services was discussed based on the need for additional emotional support following the interview session (see consent form in Appendix B).

Reasonable steps were implemented to protect the confidentiality of sensitive information shared by participants by keeping audio-taped files and transcripts locked in a private office file. Identifiers were not used to link participants to specific data, and no actual names were included in any transcribed materials.

Demographics

Participants represented life-impacting suffering stories that occurred at various intervals of their lives. The ages of participants ranged from 43 to 70 years with a mean age of 53.1 years. The sample consisted of three males (mean age of 49.6 years) and five female participants (mean age of 55.2 years). All participants were Caucasian; six persons were married, two persons were divorced. All persons offered accounts of current life-impacting suffering experiences, however they either had some additional previous experiences of suffering or they had sustained life-impacting suffering throughout much

of their lives. Three persons were not working and were receiving short-term work disability benefits during their post-surgical recovery periods; one person was in the midst of seeking diagnostic treatment options despite eight months of medical disability, and the remaining four participants had suffering incidents within the past one to ten years (see Table 3.1 for participant demographic information).

Table 3.1

Participant Demographics

Participant	Gender	Age	Marital status	Interview setting
A	Male	55	Married	Private interview in participant's work setting
B	Female	51	Married	Private, in participant's home
C1	Male	48	Married	Private in interviewer's home; wife in attendance per request
C2	Female	58	Married	Private interview in interviewer's home; husband in attendance per request
D	Male	48	Divorced	Private in participant's home
E	Female	43	Married	Private in participant's home
F	Female	54	Married	Private in participant's home
G	Female	70	Divorced	Private in public office setting

Description of Setting

Natural private settings where suffering persons live, work, and heal were sought for this study. One participant was interviewed at his work in private, and two were interviewed privately in the interviewer's home at the participants' request. The remaining participants were all interviewed privately in their own homes with no other family in attendance. Participants were given as much control in choosing their "best times" to interview where they felt most comfortable to protect their privacy and to minimize inflicting further suffering during the interview process. An open-ended unstructured interview process was implemented to promote thick, rich descriptions of participants' experiences. All interviews were audio-taped based on permission granted by participants.

Questionnaire

The following research questions were addressed in this study:

1. What are the differences in the lived experience of suffering for persons who have experienced and endured various types of suffering and life-impacting events?
2. How do persons distinguish between experiences of suffering and enduring due to life-impacting events?
3. What are the perceptions of healing and alterations in self-perception for persons based on the lived experiences of life-impacting suffering?
4. How can professional caregivers expand their awareness and assessment of enduring and suffering and convey their acknowledgement of its impact on persons who have suffered and endured life-impacting events in their lives?

5. What innovative and supportive care given by professional caregivers will be discovered as effective for suffering clients and their families?

Procedure

Data collection included one audio-recorded interview ranging from 60-90 minutes with each participant in natural settings. All participants were given the interview question schedule (see Appendix A for Interview Schedule) prior to the interview to promote deeper reflection. Participants were interviewed privately without family or friends in attendance during the interviews, with the exception of one married couple who preferred to be in attendance while each partner was interviewed separately. Additional journals related to accounts of participants' suffering were requested, if available, at the time of interviews from participants. Two participants offered copies of their journals, completed at the time of their primary suffering events, which offered additional data sources. A total of ten sources, comprised of eight interviews and two journal sources, were collected prior to coding and data analysis. Triangulation of data sources was achieved through interview transcripts, journals, and field observations and notes of the researcher's observations which were maintained following each interview session.

Ethical standards for the preparation of data prior to and during analysis were upheld through various methods. Verbatim transcripts of audio-taped interviews were transcribed without participant identifiers and member checks of verbatim interview transcripts were completed and approved by participants prior to initial inductive data analysis (see Appendix C). Veracity or truthfulness was established through material

audit analysis of transcripts and audio-taped interviews by a peer reviewer. All data files were kept confidential and locked in a private office.

Interpretive phenomenologic, or hermeneutical analysis methods were implemented to gain an understanding of the participants' shared meanings, interpretations, and experiences related to the lived experience of the phenomenon of suffering. Prior to interviews and initial inductive analysis, the author reflected upon her preconceptions about the data in an attempt to suspend preconceptions about the data to gain a better understanding of the suffering experiences of the participants.

Following the initial steps in Colaizzi's phenomenological method (Raholm and Lindholm, 1999) all transcripts were read several times to extract narrative descriptions of the lived experience of suffering. Formulated meanings, or meanings of significant statements of these descriptions, were eventually coded into theme clusters utilizing Moustakas's (1994) approach for development of "essence" descriptions to discover the meaning of the content of the narratives to enhance understanding. A constant comparison analysis method or axial coding was implemented. An audit or decision trail was maintained and investigator triangulation occurred through consultation with the researcher's dissertation advisor and peer reviewers.

Statistical Tests

Manual coding and theme identification was completed with the support of the NVivo 8 software research program (see Appendix D for statistical information related to theme analysis).

Methodological Limitations

According to Lincoln and Guba (1985, as cited by Polit & Beck, 2006), the four criteria for establishing the trustworthiness of qualitative data are credibility, dependability, confirmability and transferability. In this study the credibility of data was enhanced by prolonged engagement and triangulation of data sources with eight participants, document review of several journals, and field observations. Though most primary suffering events were physiologically based with health issues, secondary non-physically based issues also emerged. Saturation of data collection was achieved; however engagement could have been enhanced further through multiple interview sessions with participants. Persistent observations by all persons who suffer contributed to further depth in the study. External checks were accomplished through peer and advisor debriefing sessions. Researcher credibility was established through the recognized competence in interviewing skills verified through professional credentials, a prior degree in counseling, and over thirty years of nursing and educational experience.

The sample size of eight participants was small but adequate for a phenomenological study based on a unique targeted experience such as suffering. The group's lack of racial and age diversity, representing an age range of 27 years, would possibly limit the sample's diversity of individual experiences. Because persons' primary suffering events focused on physical health issues, a broader recruitment of participants with more diverse etiologies of suffering could be considered for future studies. Future replications of the study should also consider the recruitment of subjects who are between the ages of 18 to 40 years and over 70 years; more diverse minority participants should be also encouraged.

Variations in natural settings for participants' suffering also altered levels of support and financial means for seeking ways to address needs and any required health care or mental health services to facilitate coping with suffering. Differences in levels of family support or support from significant others was a variable that also presented influences in participants' altered types of suffering journeys.

Dependability of data to test the stability of data over time, and confirmability, the objectivity or neutrality of the data, was strengthened through an inquiry audit by the dissertation advisor and committee. An audit or decision trail was also maintained and documented through the NVivo analysis software program which supported the process of data reduction and eventual study findings. Attempts to bracket the researcher's biases and assumptions regarding the topic of suffering were done at the beginning of the study.

Transferability or generalizability of the study to other contexts and settings was promoted through rich, thick essence descriptions for all major themes and through careful consideration of theoretical contexts and review of the literature.

Summary

The design for this qualitative interpretive phenomenologic study was based on the need for further exploration of the lived experience of persons who have endured life-impacting suffering. Private and natural settings were provided for interviews during data collection. Measures were implemented to support the trustworthiness and validity of methodology and the recruitment of a population sample that represented persons with a wide range of diverse views of suffering, yet limited extreme deviant case sampling. Human subject considerations were made to protect the participants.

CHAPTER 1V: RESULTS

Introduction

The aim of this interpretive phenomenologic study focused on exploring the lived experience of persons who have endured life-impacting suffering events. Adult participants were interviewed to distinguish characteristics of each of their individual suffering experiences. Specific descriptions were sought regarding their unique suffering experiences and the imprint on each of their lives; their experiences of enduring or “getting through” suffering and how it was different from suffering; issues of family and professional caregiver support including examples of effective and ineffective support and care; perceptions of healing in their suffering; and self-discovery gained through their suffering experience.

This chapter will discuss the qualitative data analysis methods used to analyze the data, data results, and a summary of results. Description and interpretation based on analysis will be presented. This chapter reveals each of the eight participants’ stories and lived experiences of suffering. It offers a glimpse into their journey through, and in some cases beyond suffering, uncovering the varied and distinct characteristics of suffering they each lived and experienced.

Data Analysis

Interpretive phenomenologic, or hermeneutical analysis methods were implemented to gain an understanding of the participants’ shared meanings, interpretations, and experiences related to the lived experience of the phenomenon of suffering. Interpretive phenomenology attempts to interpret and understand the human experience, rather than a mere description of it (Polit & Beck, 2006, p. 220). Following

in-depth and open-ended interviews, verbatim interview transcripts were completed by a hired assistant. The researcher listened to each audio-taped interview several times to verify accuracy and to enhance immersion in the data. Member checks of these verbatim interview transcripts were conducted with each participant prior to the inductive data analysis.

Prior to interviews and initial inductive analysis, the author reflected upon her preconceptions about the data in an attempt to suspend preconceptions about the data to gain a better understanding of the suffering experiences of the participants. Bracketing was not completed as “it was not possible to bracket one’s being-in-the-world. Hermeneutics presupposes prior understanding on the part of the researcher” (Polit and Beck, 2006, p. 221). Following the initial steps in Colaizzi’s phenomenological method (Raholm and Lindholm, 1999) all transcripts were read several times to extract narrative descriptions of the lived experience of suffering. Formulated meanings, or meanings of significant statements of these descriptions, were eventually coded into theme clusters utilizing Moustakas’s (1994) approach for development of “essence” descriptions to discover the meaning of the content of the narratives to enhance understanding. A constant comparison analysis method or axial coding was implemented, shifting the focus between the participants’ main claims and the author's interpretation of the meaning of those claims. A computer software research program, NVivo 8, was utilized for transcript analysis and coding during this analysis phase.

The first inductive data analysis revealed nine major themes which were eventually collapsed into five major themes. An in-depth consultation with the researcher’s dissertation advisor was conducted prior to finalization of theme analysis.

Triangulation of data was achieved through multiple data sources including interviews and journals. Investigator triangulation occurred through consultation with the researcher's dissertation advisor and peer reviewers (see Appendix D for Audit Trail Letter).

Summary of Analysis

Five major themes were revealed through extended data analysis including, in order of highest frequency of percentage of interview coverage, the nature of suffering, enduring, care and support, family issues, and beyond suffering to recovery and healing. A theme table (Table 4.1) identifies each of the major themes with respective sub-themes

Major Themes and Sub-Themes

Table 4.1

Mean Percentage Interview Coverage for each theme

Major Theme	Mean Percentage of Interview Coverage	Sub-Theme	Mean Percentage of Interview Coverage
Nature of suffering	37.4	Emotional suffering	19.3
		Physical suffering	11.5
		Suffering triggers for more suffering	7.6
		Spiritual suffering	4.6
		Sensory experiences	3.0
Enduring	22.1	Shutting down	10.6
		Isolation - longing for help	4.7
		Transition to survival and living	6.8

Major Theme	Mean Percentage of Interview Coverage	Sub-Theme	Mean Percentage of Interview Coverage
Care and support	17.9	Effective care and support from family and friends	8.9
		Ineffective support and care from family and friends	3.0
		Effective professional care and support	6.7
		Non-supportive care from professionals	10.3
Family issues	17.7	Decision-making in suffering and it's impact on family	5.2
		A sense of powerlessness impacts families	4.0
		Parallel suffering	2.8
		Family tensions	3.4
Beyond suffering – recovery and healing	15.7	Adapting to changes	6.2
		Self-perspectives after suffering eases	9.3

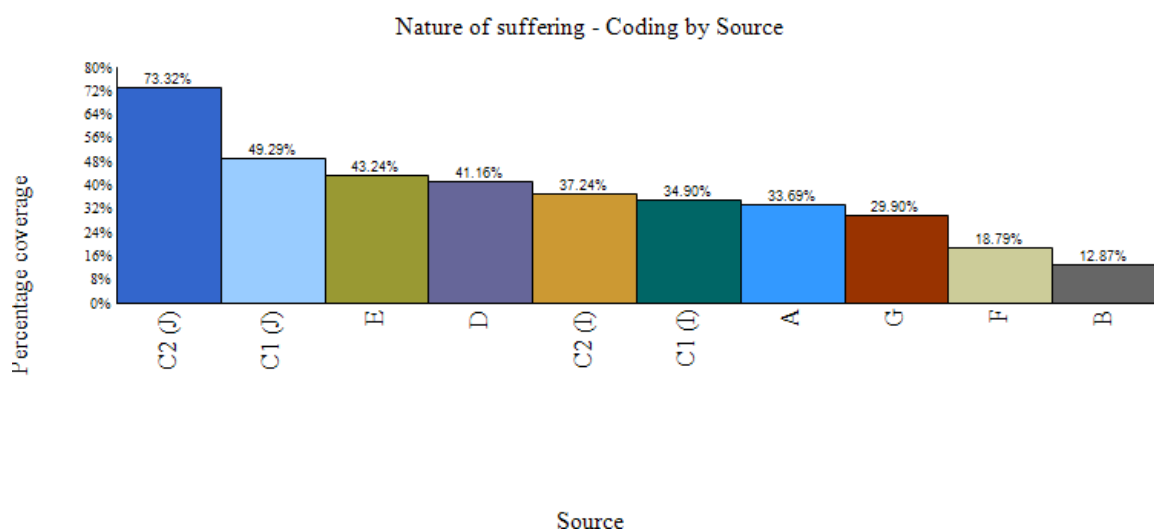
Note. Percentage totals for sub-themes don't reflect major theme totals, but indicate percentage of interview coverage during the total discussion for that particular theme.

and mean percentages of interview coverage. A narrative summary of all major and associated sub-themes follows.

Nature of Suffering

Participants overwhelmingly demonstrated a preference or need to describe the nature of their suffering demonstrated by eight of ten sources who cited this theme most frequently during interviews demonstrated by a mean of 37.4% interview coverage by all participants; and a range of 12.9% - 73.3% (see *Figure 4.1*).

Figure 4.1 Major Theme: Nature of Suffering, Percentage Coverage Coding by Source



Note: All sources, labeled by letter reflect interview sources with the exception of two journal sources (J) by two participants who were also interviewed (I).

Two interview questions offered participants opportunities to share detailed accounts of the nature of their suffering experiences: (a) Tell me about your experiences with suffering. What types of suffering have you experienced? and (b) How has suffering impacted your life? (see Appendix A). Five sub-themes related to the nature of suffering emerged in response to these two questions (see Table 4.1 and Appendix D). Descriptions of emotional suffering were of highest frequency (mean of 19.3%) and covered by all ten sources (including eight participant interviews and two journal sources). Nine of ten

sources shared physical dimensions (mean of 11.5% interview coverage); eight of ten sources related how their primary suffering events elicited or triggered further suffering in their lives (mean of 7.6%); seven of ten sources offered descriptions of spiritual suffering (mean of 4.6%); and four participants indicated sensory aspects tied to their suffering (mean of 3.0%).

The participants who had the lowest percentage of coverage on this theme related to the nature of suffering were two participants who were experiencing different levels of suffering secondary to their primary suffering. One participant's primary suffering event, a miscarriage, had occurred almost thirteen years prior to the interview. Her story was more retrospective in nature, yet her descriptions of the nature of her suffering was the second highest frequency for all five themes (18.8% interview coverage), demonstrating its central focus for her as well. The participant who shared the lowest percentage of coverage (12.9%, see *Figure 4.1*) about the nature of her suffering experienced suffering prior to and following her decision to choose elective surgeries to minimize her risks of breast and ovarian cancer. She had an oophorectomy followed by a mastectomy with some reconstruction within three months. Despite the trauma of the threat of cancer, her physical suffering was of shorter and less intense duration compared with other participants' descriptions of their primary suffering.

Emotional Suffering

Participants' accounts of a wide variety of emotional suffering indicated its far-reaching influence on their lives; emotional suffering was the most discussed characteristic of suffering by all participants and sources with the highest percentage of references (mean of 19.3% interview coverage). Yet a general failure by others to

acknowledge the significance of emotional responses to suffering was noted by most participants. One participant's primary review of his story of suffering focused on the neglect of this area throughout his suffering experience. Participants' initial reactions and their individual coping mechanisms were also described which either positively fostered a sense of hope; or in the absence of effective coping, led to depression or despair. Based on an interview question, participants were encouraged to summarize the life-impacting changes along with their recollections of their toughest moments of despair in their suffering trials.

One participant's journal entry captured the breadth of emotions illustrating how far-reaching she and her spouse's emotional suffering was during her husband's acute and post-discharge extended recovery from a bowel resection:

Scared, drained, exhausted, mentally and physically want to be alone because I felt I had to entertain everyone – frustrated with residents and not seeing the doctors. Nervous about weekend doctors who just quickly reviewed his chart and barely looked at him, afraid to leave him alone, doctor didn't keep in touch with me. Worried about mounting medical bills, worried about (son) and the house.

Fear, anxiety, fatigue, frustration, worry, and exhaustion were recalled during these days of suffering together.

A failure to acknowledge the emotional aspects of suffering was mentioned by many participants. They discussed their frustration with the lack of a holistic focus particularly for their emotional needs. A focus on cure and fixing the physical ailments superseded any attention to emotional assessment and healing:

One point I want to make more than anything else is just dealing with the emotional aspects of suffering and your pain and how closely intertwined it is with everything else. But in my experience, it wasn't addressed anywhere in the whole process...Somewhere in all the medical professionals I dealt with, all they ever concentrated on was fixing the cancer. Whereas if you're looking at the

overall picture of suffering it is more than just that, it is your emotional state of mind. It really makes a big difference.

The varied emotional responses were not often anticipated or assessed which contributed to increased frustration and yearning to feel “normal again.” The same participant expressed a desire to be better prepared to anticipate depression due to the physical trauma he had experienced:

Nobody from the family doctor, to the surgeon, to the nurses on the shift, nobody ever mentioned anything about what you should expect about becoming depressed as part of this whole thing, as a result of losing your good health, result of pain, result of the whole traumatic experience of it.

He later met with a counselor post-discharge who validated his feelings of depression as a normal part of his recovery process, “Your body hurts, you’re frustrated, and you’ve had a lot of trauma. It’s perfectly natural to be depressed.” His feelings were validated as he expressed his relief, “Of course it was kind of a relief to hear some validation that there is nothing wrong with me.” Another person struggled with unacknowledged suffering and depression for over ten years who said, “Now looking back I can see the symptoms were there. I guess I didn’t know anything about depression to be able to recognize that’s what it was.” The lack of screening and emotional assessment delayed her diagnosis and chance to heal for over ten years.

Emotional reactions to suffering. Emotional reactions to suffering traversed a wide range of emotions including but not limited to shock, fear, sadness, and crying. Shock often accompanied the diagnostic phase when participants received breaking news or updates indicating a significant change in their condition. One woman offered her responses, “I had just turned 50 and never been in the hospital and now she (physician) is telling me one day I have cancer and need a total hysterectomy, that was a shock.”

Another participant expressed his dismay with his overall health at discharge, “I was flabbergasted. I couldn’t believe it. I wasn’t able to eat properly. I had a probably five to six inch open abdominal wound. I couldn’t believe they would just send me home like that. Especially since everything didn’t feel right.”

Fear was expressed by many participants related to the anticipation or dread of suffering; medical and surgical procedures; the unknown or an unfamiliar experience; death or disability; dread of side effects or life-altering outcomes; and having to endure or persist through suffering. The anticipation of suffering was expressed by one person, “Worrying about, it is a good question, how will it change you? How it changed me?” Medical and surgical procedures presented a threat for a participant awaiting an elective mastectomy and oophorectomy, “The hardest part was when I got close to my surgery and got scared. Scared about what was going to happen.” Another participant who faced major gastric surgery offered his fear related to impending surgery, “I was confident, but still very nervous about it because it’s a big surgery.” Unknown and unfamiliar experiences presented feelings of anxiety and fear for impending surgery, “The idea of someone cutting into me terrified me. Plus, having previously worked in a hospital, I knew that many many things could go wrong. The fear of death and suffering was minimized for one participant when he was comforted by his mother’s words, “I don’t believe you’re going to die from this. You’ll learn from this and then help others.”

Very few persons talked about their sadness and crying, but if they did admit it, they often hid their tears from loved ones. One wife relayed her efforts to withhold tears before surgery, “There’s a place in my head that I go to deal with things. I don’t remember crying or being that upset.” But she also admitted, “I did break down one night

and cry, not so much about the surgery but about the future. Was this the best I was ever going to feel again? Would I come out of the surgery somehow different, those sorts of thoughts.” Her husband held back his tears until she went into her surgery, “I remember when I took her to the hospital to have surgery. I remember going to the waiting room and bawling like a baby.”

Individual coping mechanisms fosters hope or despair and depression.

Individuals shared how their ability to cope to endure and survive was fostered by a sense of control; those who established a command or resolve over their situation often fostered a positive strength, nurturing feelings of hope to endure and survive their strife:

I was just trying to steer my mind from what’s going on – that I couldn’t control, but I could control whether being positive or negative.

But others who struggled to cope battled with bouts of depression that sapped their resolve and strength to endure and survive, tending to move them towards despair and loss of hope:

Yeah, then when you put narcotics and medication, your mind starts to say there isn’t any hope you will be like this forever. It is meaningless. Who are you affecting? You’re not affecting anyone in this life anymore. Your life is not making a difference. We live in a ‘what have you done today?’ society. When you don’t do anything the failure part comes. Sometimes I don’t even think...sometimes I don’t even think anything.

This battle to hold on was influenced by one participant’s self-doubt, her lack of progress for treating her physical ailment, and the impact of medication.

Toughest moments of despair. When participants were interviewed about their most difficult time when they struggled the most (see Appendix A), their varied responses depended on the context of the suffering, moments of crisis often due to physical complications or disappointment, and the duration of their suffering. One

participant recalled his most difficult moment of crisis as “absolute despair:” He was in such pain and he said that the doctor “could have said you were dying and I would have believed it.” He further elaborated about his despair:

I remember two points in time when I felt absolute despair. One time was when I had the most intense pain I ever had. The nurses just said we understand it can be really bad; you just have to wait it out. They got the on call resident to just come to reassure me, ‘You’re not dying but it is intense pain. I understand how bad it is, but there is nothing I can do, but wait it out.’ I got really, really despondent that night in addition to feeling the severe pain. The other time was when doctors came in and said there is nothing we can find.

Facing despair threatened both the participants’ sense of hope for survival and recovery.

Reassurance from others was crucial for endurance through these very troubling moments of crisis.

A moment of crisis due to disappointment contributed to another participant’s loss of hope and most difficult time of struggle with suffering. When a participant was told that an anticipated treatment that was pivotal for relief after months of agonizing and life debilitating symptoms would be too risky to attempt, she admitted that was her “lowest of low points:”

He turned on what he said. I was in bed for four or five days, so depressed [tearful]. Since then it has really been hard to have hope. That was probably my lowest point. I had hoped...all this time, all this hope and then have them say no. that is the frustrating thing....That’s the hardest part, people not being willing to help you and not knowing they don’t know what to do with you. It’s no hope.

Hopelessness and despair were particularly impacted when physicians failed to uncover or diagnose the condition or if they had to admit they didn’t know what to do to help a participant.

The duration of suffering was also significant in several participants’ recall of their most difficult time of struggle. One more elderly participant who took her grandson

in to live with her relayed the difficulty with the length and intensity of her struggle:

Participant: At one point I took my grandson to raise for a time, for years, that was very difficult. That was in a way very unfamiliar territory for me because I'm older, he's a teenager. And I didn't have anyone else in the home to double team him and it was a very difficult time. And it was a type of suffering, I guess because it was very hurtful, it was very demanding. I worked part-time so that I could take care of him and meet his needs which impacted me financially, too. And it was tough.

Interviewer: And that affected your suffering by being involved in their lives?

Participant: Right. The stress and then the toll that stress takes on our bodies.

According to the participant, the toll for this prolonged suffering and stress, was on her physical health.

Life-impacting changes associated with emotional suffering. Life-impacting changes related to emotional suffering were expressed as grief reactions for losses experienced. Questions were raised about the future; there were multiple suffering events; and yearnings for a different life. A sense of loss for life-altering outcomes was shared:

I have a fear I'll have this for the rest of my life. I know I'll never be the person I was before the surgeries but I want to get back to a halfway normal level.

Another participant whose baby died in stillbirth mourned her loss with a delayed and prolonged depression as she commented, "So it was basically a 13 year period that it sort of persisted and progressed...I'm sure now looking back I can see the symptoms were there. I guess I didn't know anything about depression to be able to recognize that's what it was." She shared how this great loss led to a significant change in her ability to engage in life, "I couldn't figure out what was wrong because I should be happy and celebrating (the birth of her granddaughter) and I was very subdued. It was work. I made a baptismal gown and I just had to make myself do it."

Another person acknowledged fear and questions for her future, “Was this the best I was ever going to feel again? Would I come out of the surgery somehow different? Those sort of thoughts.” Finally, another shared, “Like so many others, I certainly never expected it to happen to me and I had no idea how life changing it can be.”

Reactions to multiple suffering events contributed to life-impacting changes. One participant shared how the stream of suffering events in a short time period brought him to a point of shutting down and without energy:

I kind of ran into a brick wall about March this last year. I knew I was just out of energy, fatigued. I think it was having gone through a lot in a short period of time. Mom’s death in November, and then trying to get things arranged so Dad could be taken care of without Mom.

In response to multiple complications and an extended recovery process, one participant expressed his desire to get beyond the multiple sufferings in his statement of yearning for a different life, “to just get out and be normal again.”

Physical suffering

Physical suffering was the second highest sub-theme stressed during accounts of the nature of participants’ suffering (mean of 11.5% interview coverage). There was a broader variance in participants’ emphasis of their physical suffering with a range of 30.8% to 2.2% of interview coverage, which appeared to coincide with current versus retrospective accounts of suffering respectively. The four participants who offered the most in-depth descriptions of the physical nature of their suffering also exhibited the highest levels of suffering with the most complications due to their primary suffering events. The participant who shared the highest percentage of coverage about the nature of her suffering (73.3%) covered extensive suffering descriptions in her journal completed

at the time of her suffering as she experienced her own major suffering due to cancer and chemotherapy. Following her fifth of six chemotherapy treatments she recorded the following journal entry:

I did not realize that I didn't feel that well. Usually the Monday after treatment is a hard day for me. I'm able to make it to work but it takes everything that I have to keep my eyes open. I'm usually so tired.

At the completion of her sixth and final chemotherapy treatment, the participant recorded some of her fears about fully recovering from her ovarian cancer:

Chemo #6. LAST ONE. Doctor's visit. I was anxious to see him and have this week over with so I can go on with my life....Before going to the doctor I went through all the worries about things not being okay, this being prolonged. Also they are going to be taking away some of my security blanket. As long as I had the chemo I felt that nothing had a chance to grow in my body but now that won't be there.

Several years following her cancer, she then supported her husband through several major surgeries and post-surgical life-threatening complications and offered this description of her husband's physical suffering and its impact on her in this journal entry:

[He] seemed to be fading right in front of me, he was pale, couldn't get comfortable, couldn't move without pain, was having shortness of breath....Finally left the hospital late in the afternoon of May 13 (38 days of hospitalization and 3 surgeries). He looks like he has been in prison camp. He is very thin and weak and moves very slowly...very weak, tires easily, not much appetite.

Her spouse offered his own journal description and the second highest percentage of coverage (49.3%) related to the nature of his suffering:

The suffering that I endured after the surgery was pretty intense. I went into septic shock and was down for about a week. Coming back after that was probably the most difficult time...I know since surgery there hasn't been a time without some kind of pain because of the massive amount of surgery that has gone on.

Pain was a primary concern and a constant for him throughout his recovery.

Two other participants followed fairly closely in their emphasis of coverage on the nature or description of their physical suffering (43.3% and 41.2%). One of these participants also experienced complications for over six months following the onset of his suffering events with multiple complications. He shared his struggles to eat and manage his pain:

The whole time I was in the hospital after I was re-admitted for that three weeks, I didn't eat at all so it mostly was the space for two months that I was not able to eat at all...After the first surgery I was pretty well medicated the first week or so and so I don't recall any intense pain or anything I experienced then. But when the side effects from the undiagnosed blockage started kicking in I had bouts of some very severe pain, probably the worst pain I ever experienced. That was pretty bad...when you're in that much pain, you can't even speak.

Another participant shared how the onset had been two years ago, but her recent more intense suffering had been at least eight months in duration with delays and difficulties in clearly diagnosing her condition resulting in an inability to proceed with effective treatment:

I started with headaches two years ago. But I was starting to get better...the last eight months it has been non stop, constant bedridden and can't work. The headaches before at least I could function....Some days it's so painful I can't get my head off the pillow. Once in a while I have a good day and I can do a little laundry or empty the dishwasher. But that is about it...everything is an effort. Things that used to be so simple. I look at the dishwasher that needs to be emptied and think how am I going to get this done today. It is such a challenge.

Her physical description of the pain reflected her helplessness in the constant agony of her suffering:

The ongoing, never ending pain, when the spasms are going from the moment I wake up to the moment I go to sleep. They have been timed from every four to six seconds. Sometimes it actually takes the air away from me. There is the physical, the constant, it's like constantly doing abdominal exercises all the time.

Each of these four persons endured high and intense levels of suffering with multiple delays in healing and recovery before they could resume their former activities. One of these four persons was able to work full time at the time of the interviews. The other three persons were still on short-term disability from work.

Suffering triggers further suffering

In response to the interview question, “What other issues or concerns surfaced for you at this time (See Appendix A), participants offered accounts linking one suffering event with others, illustrating how suffering events potentially served as triggers for more suffering. These results indicated this is as the third highest sub-theme for accounts of the nature of the participants’ suffering. The mean interview coverage (7.6%) was shared by eight of ten sources, with the highest emphasis by one participant (29.9% coverage per journal entry).

Participants shared how suffering events elicited further suffering and also extended an undesirable influence on other family members. Accounts focused on how their own original suffering events triggered additional suffering incidents, either due to complications related to the original suffering experience or additional non-related suffering experiences. It was as if their suffering multiplied and infiltrated other areas of their lives. Another way that suffering extended its influence was through its inter-relational nature, touching not just one but other persons in families or close relationships. Suffering often rocked through family member’s lives, creating even more turmoil and chaos.

Accounts related to extended or prolonged suffering were primarily attributed to physical complications or delays in diagnosis that resulted in prolonged hospitalizations;

financial stressors; disability from work and delays in returning to work; infections; and additional surgical procedures. The effects of these complications left a trail of additional stressors including financial worries due to living on disability pay for over three months; back pain and the need for chiropractic care; and disruption in intimacy with a spouse.

Another participant, who experienced a recent divorce prior to being diagnosed with colo-rectal cancer with ensuing chemotherapy and radiation, was discharged after three consecutive surgeries that left a massive infected gaping abdominal wound stated, “If you could name a complication, I pretty much had it.” These multiple surgeries and complications resulted in the following effects: concerns with kidney function; a total of three bowel surgeries, weight loss of over 30 pounds, an abdominal wound infection, disability for over six months, financial strain, and depression. He related, “I didn’t eat at all...for 2 months that I was not able to eat at all,” and he relayed his fear that “they’re going to let me starve to death.”

A third female participant experienced many life-impacting changes and losses due to being home-bound for eight months while awaiting final diagnosis and treatment for severe headaches and clonic spasms. She stated, “I lost my independence. I can’t drive a car. I can’t go anywhere by myself. I always have to call for rides. I feel like a little kid again...the hardest thing is missing out on your kids’ events.”

Suffering also contributed to further suffering when distinct suffering events beset more than one family member simultaneously, or different members would experience the same type of suffering at staggered intervals, trailing one another. According to one male participant, his family was impacted with distinct multiple events when his father experienced a cerebrovascular accident (CVA) surviving more than five years while

dependent on his wife and caregivers to avoid nursing home care. After five years his mother, who the participant stated was “just going nuts” with the burdens of caregiving, developed a jaw infection and cancer. She refused cancer treatment and died several months later, leaving her physically dependent husband’s care to her sons. The participant, who had survived Leonard’s lymphoma and serious cardiac issues, was now one of the three sons who would walk through the decline and death of his mother, while offering support and help to all of his remaining family members. He related, “Yeah, so there were a lot of plates spinning...and it wasn’t that you just had one thing that you could concentrate on. And that’s probably what you find out happens, death sets off a series of events.” He had to negotiate inheritance money from his mother prior to her death to pay for his younger brother’s substance abuse treatment that he arranged, “I think the move up here derailed him and he didn’t say anything but the way he acted it out was just drug and drug behavior and that type of thing.” His oldest brother was not available to help him either, “My oldest brother was there but we were picking up the pieces on him, too.”

Another participant’s family lost three generations of women in their family to breast or ovarian cancer including a grandmother, mother, and sister. When genetic testing predicted a high cancer risk for the participant, she revealed some of her experience due to these multiple, yet distinct suffering events in her family:

At a young age I lost my mother to breast and ovarian cancer. My sister was 52 when she found out she had ovarian cancer. And my grandmother died of breast and ovarian cancer...I don’t think I suffered with that. But that whole trail through the family. Of course with any loss of cancer there is a period of suffering. It is not pretty at all, going through that with them, deciding what to do.

The impact of losing all female family role models so early in her life had far reaching consequences that also affected her as well as her relationship with her own daughter:

Yeah, I didn't have a role model; I don't know...I didn't have anybody to correct me. Maybe I was hard on her. Grandmas have the unconditional love. My husband lost his mom so they didn't have any grandmas to be a buffer, a role model. I didn't know I didn't have a role model until now as I'm older. I would have acted differently.

Multiple suffering events, either reoccurring individual ones, or a trail of family members impacted by distinct suffering experiences, do appear to have far-reaching consequences and life-impacting results.

Spiritual suffering

A fourth-ranked sub-theme for the nature of suffering, spiritual suffering, was shared by seven of ten sources with a mean interview coverage of 4.6% (see Appendix A). The range of interview coverage spanned 8.4% to 1.6%, reflecting less emphasis on the topic, yet participants revealed how significant this spiritual component was in their experience in suffering. These accounts of suffering's imprint on their spirituality focused on two main areas: (a) a connection and trust in God or a higher being that impacted one's sense of hope; and (b) a desire to gain some understanding of the meaning of the suffering for the purpose of sustaining hope and strength to endure or to seek comfort.

An acknowledgement of how suffering can pull one away from God and threaten one's view of their faith and sense of hope was offered frequently:

Sometimes the scriptures sound so empty. I read them and they're so full of hope, and I never lost hope before. I think that is not for me anymore. God keeps saying it is. All promises are for us all. It's really hard. It is hard when you can't go to church. It's hard when you read and it feels so hollow. And it's hard when I know people are praying for me. But they're not holding my hand like you did. (crying) They're not here holding my hand.

Another participant offered how the hospital setting interfered with his ability to connect with God. He shared, “Normally when people pray or have those moments of meditation, it is quiet moments in a relaxing atmosphere. Those are two things you don’t have in the hospital.” When one participant was questioned about feeling a disconnect with God through her experiences she related a fear of being angry at God through her statement, “No, I tend to be more, I need you here with me then I’m angry because if I am angry and I turn away then I don’t have anything.” She leaned in to the interviewer and offered, He (God) was right there with me.”

Prayer was mentioned often, either for oneself or prayers offered on their behalf by friends and family members. One participant shared that “people were there praying and caring,” and another stated, “I remember asking them all to pray for me.” Yet, it was hard to maintain that prayer when alone, “Praying and trying to put it in perspective, but it was so hard especially when no one was around.” Suffering presented a struggle to practice and maintain religious routines such as prayer; one participant related a personal history of substance abuse treatment that had resulted in the establishment of spiritually-oriented support group that positively impacted his recovery from addiction. Yet, when faced with a serious illness with many complications, he relied on their overwhelming support to boost his ability to maintain a connection with his higher power, rather than merely surviving:

That right there is probably the biggest benefit I got from my friends in the program coming by. It is a spiritual program and stresses your contact with a higher power. And face it, when times get really tough, when you face serious adversity, if you have any type of faith a lot of times that is one of the first things you shrug off. People from the program come in and reinforcing that link reminds you, you need to keep in contact with that faith and your higher power.

Persons who have faced times of deep levels of suffering or despair, have often relied on others to pray for them when they either physically couldn't pray or even speak for themselves. Another participant who spent weeks in intensive care following three different surgeries, offered how he lacked hope to get better but that prayers were critical, "It means so much, those prayers are my only lifeline." Another person shared, "Just knowing all these other people were praying for me helped. If I couldn't pray myself well, then maybe somebody else could pray for me to get through it and be well. One significant account of supportive prayer involved a couple who shared prayer with the husband's surgeon prior to his surgery, "She prayed with us in the office and before surgery."

In the midst of struggle, persons sought to gain an understanding of the meaning of suffering for the purpose of sustaining their hope and strength to endure or as a means of comfort. Finding meaning also helped one see some purpose for their suffering beyond the immediate pain and discomfort. One participant relayed her assurance of God's love, but the yearning for God's purpose in her experience, "Yeah, I've never ever lost that God loves me no matter what. Sometimes I say if you want to teach me something could you do it a little faster?" One participant with lifelong faith, shared what meaning or design they viewed in their own encounters with suffering:

I know that suffering is part of God's design to make us better and more complete and more dependent on Him because we get pretty cocky and arrogant. Don't we? And so I guess I know that the main part of who I am is spiritual. I know that more all the time but I do get distracted when I hurt. Don't we all? And so I just know that.

Another person of long-standing faith offered her thanks for a temporary perspective of

suffering supported by her faith perspective:

It [suffering] makes us very introspective and poor babyish and it's just so refreshing to know that our suffering is temporary. It isn't forever. Thank you, God. And I don't know even just telling you about these things put it back into perspective, you know. It does, really. I've known that all the time but thanks for helping me remember it.

A recognition of the temporary nature of suffering comforted this participant and helped her to gain a new perspective for her situation.

Sensory experiences related to the traumatic nature of suffering

The final sub-theme related to participants' recollection of the nature of their suffering was the sensory experiences related to the traumatic nature of suffering which was offered by four participants with a mean of 3.0% interview coverage (see Appendix A). Two participants, married to each other, offered their vivid recall of the sensory aspects of their suffering in 6.5% and 4.2% coverage of their interviews, while two other participants indicated this aspect in less than one per cent of their interview coverage. Although this sub-theme wasn't representative of all participants' experiences, the time and emphasis of these participants' focus on this aspect of suffering warrants some discussion.

Descriptions of sensory aspects of suffering, or types of "sensory memories," included sounds, voice recognition, touch, visual images, and smells. Sounds, such as music and voices, served as triggers to memories of suffering, and sometimes limited the participants' tolerance for pain and other situational factors at the time, as described by

one participant:

When I was suffering, I couldn't listen to a lot of anything. I would turn soft music on to see if I could tolerate it. I couldn't tolerate it with (my wife) there. I couldn't have the TV or radio on. I could only listen for a few minutes at a time to see if I could tolerate it.

He went on to offer an explanation for his sensitivity to listen to particular music and television programs:

I think in my mind when I grew up I was told what you think about gets tied into music you listen to. If I listen to music what I normally enjoy and listen to, when I was suffering it would bring back memories and put me back into that situation again. I didn't want to feel that again. I think that is why I did that. I felt that way.

His wife also connected music to the couple's suffering experiences:

It has made us more spiritual in that there are songs that are so touching when (husband) was sick. I can still hear that song. I love that song, but it always brings me back to that time. There are times at church we hear a song. You want to be there, but you cry.

She expressed how it offered her more comfort and spiritual support despite the recall elicited about their suffering:

Voice recognition was also apparent for at least one person who had an experience of an on-call physician responding to him during one of his most difficult points of pain and distress during a hospitalization: "I still remember him now, or his voice. I didn't remember his name but I remember him making rounds one other time and I knew immediately who it was." Another recollection of speech was tied to memories of intense pain. Two participants recalled the intensity of their pain was so great that it impacted their ability to speak, "when you're in that much pain you can't even speak."

Touch was another sense that was described as significant. During times of great pain one participant was very sensitive and his wife stated, “It was hard because we couldn’t touch him because everything hurt. It was hard to comfort him.”

Images also evoked memories of suffering. Recollections of watching his wife’s hair loss were especially painful for her husband, “[Memories] are still etched in my mind. I can tell you the days for [my wife] and her chemo. Sitting by her side and watching her hair come out. Watching her go through that was awful.” Another example of the powerful impact of images relates to the contextual impact of the hospital room setting: “We went to the hospital for something. My Mom said, ‘I can’t go down there. That’s where we were when they gave us the news. That was six or seven months later.’” Another female participant explained how the image of her grandbaby’s birth impacted her, “The birth of that baby brought back the memories of the baby that we had lost and so that I kind of hit the wall.” This powerful memory’s impact was felt more than 13 years after the suffering due to the loss of her own child, and resulted in triggering a major depression.

Smells were also a powerful “sensory memory” trigger. During the wife’s cancer, she recalled her heightened sensitivity to smells. Her mother had applied lotion to her feet after surgery in the hospital. She said, “Three months after my surgery my Mom, she pulled out this lotion and rubbed my feet in the hospital. She put it on my hands and made me nauseous and made me almost throw up. I can’t stand the scent of lotion.”

The intensity and types of suffering events impacted participants’ sensory experiences of pain, grief, and other suffering experiences. One male participant shared, “That suffering to this day is so embedded in my mind. It just brings tears to my eyes

because I realized how hard it was to be in the hospital room.” These “sensory memories” elicited vivid recall and triggered memories and the traumatic feelings persons suffered in their original suffering event, as if they were back in that moment or experience. These memories were inescapable once they were provoked, propelling persons back to the pain, grief and trauma again and again as depicted by one participant, “To this day when I walk into a hospital, my skin just crawls, the smells, the atmosphere.”

Participants shared accounts of intentional attempts to avoid the triggers for these “sensory memories” to minimize their pain and post-trauma recall:

Emotionally I catch myself thinking about suffering that went on in the hospital. I can't watch programs of people suffering. It was so much like me. I feel their pain and know what they're going through. All of a sudden I'm going right back through it. I don't want to do that.

Another account offered how one participant intentionally detached to cope:

You try not to think about it. I can relive every single day of him being in the hospital all the time. I can see doctors and nurses faces. I can see him laying in bed. I can remember all the surgeries. I have to fight to keep it in a little box in back of my head and not bring it out. There is no reason to bring it out. There's still things that trip your memories.

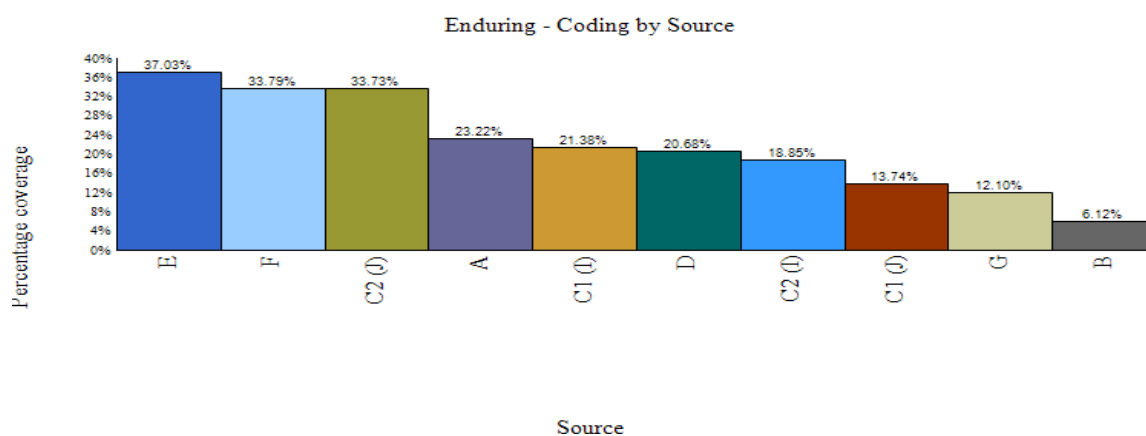
Even when one tries very hard to intentionally suppress the vivid memories, some memories can't be repressed and re-emerge into one's consciousness causing further distress. These memories related to varying time intervals for different suffering events and there was no reference to distinguish between the impact of time between events and the ability to recall these memories.

Enduring

The second most frequent theme of five major themes (mean of 22.1% interview coverage), was a significant emphasis for five of the ten interview sources. Participants

were posed several questions related to enduring in an attempt to distinguish it from suffering (see Appendix A). One participant, who offered the most extensive coverage (37.0 %) was closely followed by two other participants at 33.7% and 33.8% interview coverage (see *Figure 4.2*). These three participants shared descriptions of enduring that revealed levels of high suffering intensity with long durations; delayed diagnosis and treatment that resulted in prolonged pain and isolation due to inability to work; and multiple surgeries with post-surgical life-threatening complications that threatened their ability to endure and survive. Two additional participants who offered extensive descriptions of enduring (23.2% and 20.7%, see *Figure 4.2*) also suffered prolonged and multiple suffering events. Descriptions related to etiologies for enduring were polarized; either due to the intensity of suffering with the accompanying threat of death for two participants; or a fight to endure due to the overall duration and life-impacting nature of their suffering for all other participants.

Figure 4.2: Major theme: Enduring, Percentage Coverage Coding by Source



Note: All sources, labeled by letter reflect interview sources with the exception of two journal sources (J) by two participants who were also interviewed (I).

The participant who offered the least emphasis on the theme of enduring (see *Figure 4.2*) suffered due to elective surgeries to avert the threat of breast and ovarian cancer. She emphasized how crucial the decision-making process was for her and her family which may have contributed to her ability to get through her suffering more easily due to the heightened sense of control in her suffering process and also the shorter duration of physical recovery needed to resume her usual life routines.

Three sub-themes emerged in participants' recollections of the enduring state: the process or state of shutting down physically, emotionally, and spiritually; a sense of isolation and longing for help; and their transition to a state of survival or recovery.

Shutting Down

When faced with some of the toughest and most trying moments and phases of suffering, participants offered recollections about making an escape or hiding, going under, not having a voice, or shutting down physically, emotionally, and spiritually. A term one participant used to label this state was "absolute despair." He remarked that he experienced two specific points when this absolute despair set in. One moment of despair was due to "the most intense pain" and despondency he'd ever had, when he was supported by several professionals who reached out to him:

The nurses just said we understand it can be really bad; you just have to wait it out. They got the on-call resident to just come in to reassure me, 'you're not dying but it's intense pain. I understand how bad it is but there is nothing I can do but just wait it out.' I got really, really despondent that night in addition to feeling the severe pain.

His statements reflected not only the depth of emotional suffering, as earlier noted, but also captured this 'shutting down' theme of the enduring phase when he felt "absolute

despair” after his doctors told him that there was nothing they could find or diagnose despite his gravely ill condition.

Other participants alluded to this period of shutting down in the face of suffering with a variety of phrases including running into a brick wall, detachment, being without hope, feeling very subdued, feeling like something broke, just barely able to function, and feeling like nobody was home. Some persons’ experience of shutting down was physically based; some was emotional or combinations of emotional and physical; while one person alluded to spiritually shutting down.

Physical shutting down. Physical experiences of shutting down ranged from intense and consuming pain, lack of energy or complete fatigue, inability to listen, inability to speak, inability to cry, inability to stay awake, and even the inability to move or function. When several participants found themselves in the midst of intense and consuming pain, they exhibited this “shutting down” as their ability to focus and concentrate diminished, and only being able to respond in the moment. One said, “I had to take it moment by moment, because that’s all I had.” Time moved very slowly, minute by minute, “I never experienced time drag so slow in my life until the time I spent in the hospital.” For one person, if and when relief came from the pain through medication or other means, sleep ensued immediately:

At times pain was so great I was incoherent, so much pain, and I couldn’t focus. The only thing I could focus on was when that clock was going to tick and I was going to get some kind of relief. I needed relief from pain. I was consumed by pain. I was just shaking being in so much pain. I would work myself into such a frenzy. I was so tired by the time they actually gave me the medication. All I could do was fall asleep. One minute I was awake and then sound asleep. I was so exhausted.

Another participant compared the intense pain with being very close to dying as he recalled, “I hurt so bad that I could have been dying and I don’t think it could have hurt anymore.” If no one was around to offer a distraction, time also felt like it was suspended:

When the suffering got to the point where there was nobody around, nobody in the room to talk to, those moments almost seemed like an eternity. The only way to get past some of that was to listen to music that was soft and soothing, walk, or changing my position in bed sometimes would relieve the suffering enough or to endure even just ten minutes and be OK.

Intentional actions and decisions to fill the time were necessary during these challenging moments to bear the brunt of the suffering.

Other recollections of a physical collapse during the enduring phase of suffering involved fatigue and loss of energy after a series of suffering events in a short period of time. Sleep was common during this time of shutting down, sometimes due to effects of medication or depression. A mother recalled her inability to get out of bed to help her three kids get ready for school early in the morning. She relied on her older daughter but said, “I couldn’t get out of bed and so my oldest basically was the mom. I felt guilty; I felt horrible. I should be the mom but I just couldn’t get out, but then I went to sleep all of the time.” Another male participant offered how he lost his strength and couldn’t eat, even though he tried very hard:

Ultimate lowest because I couldn’t eat. No matter what we tried, I didn’t have an appetite, and felt like I had no strength to go any further to push myself, to push myself to do something. We tried one thing after another but nothing seemed to grab ahold of what was going on.

An immobilization or inability to function occurred for some persons. One participant recalled utilizing television to define time and to direct her daily activities when alone:

Sometimes I realize I may have been sitting here for a half hour thinking I am thirsty, I need to get up and get a drink, but haven't gotten up to get it. I've thought it. That is one reason I watch television. There is a starting and stopping point. That helps me.

Another person's account of her inability to function was being able to force her functioning for public view, but a collapse ensued when back home alone, "I could just barely function. I didn't let other people see that. I functioned in public when I needed to and then I went home and crashed."

Listening and speaking were impacted in this shutting down phase of enduring. "When I was suffering, I couldn't listen to a lot of anything. I would turn soft music on to see if I could tolerate it...I could only listen for a few minutes at a time to see if I could tolerate it." In some of the toughest moments of enduring, four of the eight participants noted how their ability to speak was either totally absent or diminished. The comment, "when you're in that much pain, you can't even speak" summarized how pain robbed them of the ability to communicate in their hour of greatest need. One person with limited energy expressed that she didn't want to waste her energy on talking, "to use the energy just to talk."

Participants occasionally cried during the interviews or became tearful, but expressed very limited emotion in respect to the deep level of suffering they recalled from this enduring phase. It appeared that they physically struggled to cry at this time or

even in their review of this period. One participant realized this in her comment, “I don’t remember crying or being that upset.”

Emotional shutting down. Descriptions from participants that related the emotional phase of shutting down during enduring were varied, but all alluded to a sense of detachment, avoidance, or non-feeling: a subdued state; or feeling different as “not oneself.” One participant, still enduring a current suffering event, realized how her emotional state vacillated, “Emotionally I feel I have a few good hours, and then it goes down hill.”

Emotional detachment fostered a way to escape the reality of the situation for one person, “I detach, I think that is how I get through part of the stuff with my husband. It’s like it is not really real.” Many participants sought to avoid facing their emotional pain through their statements of “you try not to think about it,” and “it was very painful and miserable and I don’t dwell on that.” One person shared how she shut down during her chemotherapy treatment, “If I think about the chemo and all that stuff when it was going on, I would become hysterical. If I just let it loose and let it overcome me. I would just scream hysterically and just let that loose.” Her choice was hysteria and screaming or the non-feeling state of avoidance. This loss of “not feeling the suffering” lingers today for her as she expressed, “In order to get through all this, some part of me has shut down. I can sense it a lot but just can’t seem to get it back. Maybe part of it is not feeling like I want to feel and maybe part of it is just emotional.”

A participant experiencing a depression offered her comments about feeling very subdued for what should be a very happy occasion, the baptism of her first granddaughter, “I was more subdued. It was work. I made a baptismal gown and I just

had to make myself do it.” She also noted the absence of self, which was observed by both her and her husband, “Basically wasn’t anybody home. He wondered what had happened to his wife. Neither of us knew where she went.” Another participant connected this sense of self to her physical condition, described it as “I lost so much of myself because I am so weak.”

Spiritual shutting down. There was very limited recall of episodes for shutting down spiritually with the exception of a sense of significance as a person due to loss of hope. One person became tearful as she remarked about her loss of hope, “But the other part of me has a hard time (crying) with hope. Sometimes I tell other people to have hope for me.” She also goes on to expand on how this loss of hope threatened her significance later in the interview:

...your mind starts to say there isn’t any hope, your life will be like this forever. It is meaningless. Who are you affecting? You’re not affecting anyone in this life anymore. Your life is not making a difference. We live in a ‘what have you done today society?’ When you don’t do anything, the failure part comes, sometimes I don’t even think...sometimes I don’t even think anything.

Her hint of how this loss of hope diminished her self-significance contributed to her checking out, to not even think anymore.

A sense of spiritual detachment was also expressed as remoteness from God, and the physical touch of another person, “And it’s hard when I know people are praying for me. But they’re not holding my hand like you did [crying]. They’re not here, holding my hand...those prayers are my only lifeline. The isolation when you are suffering, it makes your mind play tricks on you.” Other participants expressed similar feelings of detachment from God or their higher power.

Isolation – Longing for Help

During the enduring phase of suffering, a sense of isolation was commonly expressed by participants, particularly those with extended suffering and longer recoveries. Isolation was expressed as an actual loss of relationships or a diminished number of interactions with significant persons in their lives. Isolation was also felt as unrecognized needs, where other persons were unable to identify or acknowledge the participants' needs, which contributed to feelings of separation from others. It also impacted whether those who suffered were able to sustain enough emotional and physical energy required for meaningful interaction with others. Finally, this isolation appeared to contribute or even cause an increased difficulty to ask for help.

An actual loss of relationships or a diminished number of interactions with significant persons in their lives was common for those who endured prolonged suffering, and also spent a significant time at home in their recovery. This was not desired, but did occur as one male recalled, "I don't recall wanting to be left alone...just getting out of the house, those things incrementally contribute to an improvement on my outlook on things." A young female participant who was homebound for over eight months expressed a deep sense of isolation from significant others in her life:

After eight months, you fall off people's radar. At first they are there and concerned and call you. And after awhile when you're not there, you fall off the radar and people don't expect you to be there. I lost touch with so many relationships. People would come over at first that aren't coming over anymore.

The length of her illness and the fact that she was homebound and immobile also impacted her sense of isolation.

Some persons struggled with unrecognized needs, where persons around them either failed to identify their needs or were unwilling to acknowledge or ask about their needs, furthering their sense of separation from others. Following the death of her full-term infant, the mother recalled this lack of response to her needs, “Most people didn’t know what to say so most people didn’t say anything.” Her needs were not verbally recognized in a way that was helpful to her in her time of need, and a long-term depression followed. Another variable that could have contributed to this limited interaction with others was due to limited emotional and physical energy reserves required for meaningful interactions with others. Sometimes when persons offered themselves and reached out to make contact they were refused due to choices made by participants to conserve their physical and emotional energy for other tasks besides visiting. One person shared, “It’s hard for me to get up enough to have people around. And so sometimes I don’t want company.” But this also limited this participant’s feelings of being understood along with recognition of their changing needs due to lack of interaction. Finally, another person recalled, “I wonder, do they see the needs sometimes or is that a difficult thing?”

For some, this sense of isolation made it more difficult to ask for help or was caused by an inability to express one’s needs more openly. There was a loss to know what to do because this isolation was a new experience for many persons. Participants were limited by a reluctance to share their pain and from asking for help, and this was

recognized:

I probably didn't share what was happening to me with anybody. Well I often wonder what would have been different if I would have recognized that what was happening to me were symptoms of depression. If I would have been more straightforward about what was going on in my life and free to share that with somebody.

This limited comfort to disclose needs also prevented participants from receiving hope from others when it was needed, and thus extended further isolation. Even persons who maintained relationships struggled to ask for help as one person shared, "I'm sure if my friends knew how hard it was they would be there. It is hard to pick up the phone and ask for help." A statement by one participant captured the impact of this isolation and how it blurred with the suffering, "Sometimes the isolation becomes so entwined with the suffering that I couldn't tell the difference between the two."

Transition to Survival and Living – Moving Beyond the Enduring Phase

A distinct difference was noted as participants recalled themselves transitioning towards survival and living, from the immobilizing, shut down phase of enduring beyond some of the toughest moments of their suffering ordeal. This transition to survival required action and an awakening to themselves and their spirit within, along with a mobilization of strength and motivation to fight back. Some persons found this strength and motivation within themselves; or from their faith, family or friends; or even through the ability to seize a special opportunity.

The mobilization of strength and motivation often preceded persons' actions and ability to push back against suffering. The transition from enduring to survival was

reflected by a subtle change in verbal expression. Another person recalled this transition:

I was determined to get to the ‘what do I have to do to feel better stage’ and concern about is this the way it’s always going to be now? ...How am I going to be able to take care of myself? What does this mean financially? What does this mean socially? What does this mean in every facet of my life?

Self-motivational statements that participants shared included, “Somehow we’re going to get through all this, I’m lifted up and at my best when things are toughest, and you have to believe it will be ok.” Several persons relayed how significant their faith was in being able to resume their strength and motivation towards life and recovery, “How we made it through was only God’s hand. God’s hand on the whole thing.” Another male participant leaned on his Alcoholics Anonymous support group who reminded him to keep contact with faith and his higher power to counteract that struggle to give in to the suffering.

A change in the ability to express emotion again emerged, almost as if that cleared the path to begin healing for one couple after the wife’s cancer treatments ended:

I finally broke down and told him that I have never felt uglier, with the scar and no hair and that it upset me to think of him looking for someone else; we did a lot of talking and mending. I feel loved again, and I understand that he was missing those feelings also.

This transition was a tender stage, where persons expressed great vulnerability in their condition. As one participant’s depression started to ease, she expressed her fear, “I need to really be careful about getting too close to the edge because I’m basically on the edge all of the time and any extra stress will put me over.”

The actual transitional step away from enduring to a survival and living in suffering mode was often dependent on the suffering person’s ability to press ahead or fight back. This involved action, a decision or commitment, and the ability to see progress in these small gradual steps forward and away from enduring. Recognition of

this gradual process towards recovery or normal living was shared by a male participant in the midst of his long recovery, “As I’m getting better, re-establishing normalcy, I guess it will be an incremental thing. As I get more in control of all the aspects of my digestive system and everything, I’ll slowly build up enough confidence to get out and do more and more normal activities.” This transition was described by several persons as a turning point, “It was a small turning point, still a lot going on. At least at that point, maybe just maybe I might get through this.”

Persons described how they shifted between the states of enduring, suffering, and even recovery. This transition involved trial and error as one participant learned how to resume what had been lost to suffering as he recalled how hard it was to get moving again, “Let’s do this. I’m ready even though I know I am going to suffer. If I tried any other way, I couldn’t move. So I would count to three on everything.” Self-talk was noted as persons moved out of the enduring mode. It was a significant but discreet turning point. Another person recognized how crucial her own advocacy was as she pressed ahead for treatment and recovery, “You have to be your own advocate and demand what’s rightfully yours...so I said I can tough it out, I’ll be alright.”

Once persons had definitively moved from enduring towards an observable pursuit of recovery and from suffering towards a former or revised lifestyle, there was more work to regain life back. Several persons shared how resuming work or striving to resume work was vital in their recovery, and was also financially essential. The participant who underwent chemotherapy was able to continue working which she attributed to saving her, “I think that saved me, that I knew I had to get up and go to

work. And I had to get better.” Another person who missed months of work stated, “But financially I had to go back to work as soon as I could. I didn’t have any disability.”

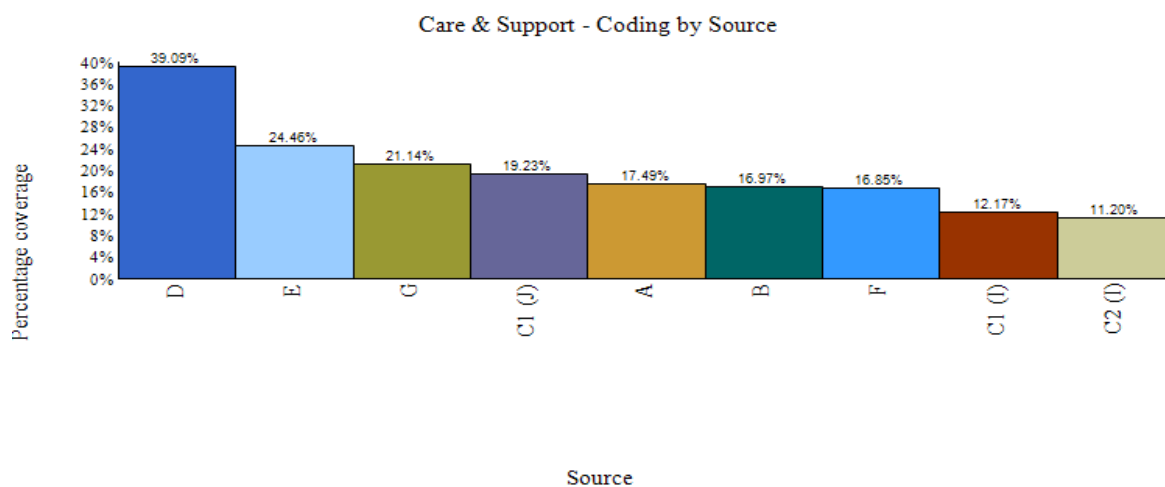
Enduring distinct from suffering?

In response to one of the research questions, “Is enduring suffering different from suffering?” (see Appendix A) participants acknowledged these two concepts as two separate states. Their descriptions of enduring reflected clear distinctions from suffering, yet suffering was always looming either just beyond enduring or intertwined with it. Enduring was described as a state of resting, pausing, shutting down, holding on, getting through, escaping, or hiding; while suffering was feeling, expending, interacting, experiencing sensations and pain, and despair.

Care and Support

The third and fourth most frequent themes, care and support and family issues, were very close in mean frequency of interview coverage; 17.9% and 17.7% respectively (see *Figure 4.3*). Care and support are fairly closely linked to family issues because family members are such central figures of support and encouragement for their families. Several of the open-ended interview questions related to this theme and requested information about how others had responded to them in their suffering experience, what they wished that others would have said or done for them, and how professional caregivers responded to them.

Figure 4.3: Major Theme: Care and Support, Percentage Coverage Coding by Source



Note: All sources, labeled by letter reflect interview sources with the exception of two journal sources (J) by two participants who were also interviewed (I).

No participant ranked care and support as their highest theme based on their frequency of interview coverage, but one person clearly offered it as their primary concern (39.1 % of interview coverage). Three of the four participants who emphasized the greatest significance for care and support during their interviews (see *Figure 4.3*) also focused more on the enduring aspects of their suffering, hinting at a correlation for a heightened need for care during the challenging phase of enduring. One other participant did not offer as much information about enduring, yet shared her struggle to wait for treatment as she self-treated her physical ailments. She also watched family members suffer through life-long emotional struggles and drug addictions while she had limited personal support as a single, elderly mother.

Care and support from family and friends

Effective care and support from family and friends. Outcomes for meaningful and effective support from family and friends during suffering centered on regular and frequent interactions with simple gestures of support such as meals, cards, and gifts. Family roles varied because all participants were not married, but roles of spouses, parents, and children, as well as the role of friends, were very significant to all participants.

Family support and relationships. Regular presence, and at times a constant or daily presence, was desired from family members during times of intense suffering and need. Types of family roles and relationships varied between participants, but the significant role of mothers' support during suffering was noted by four middle-aged participants. One of them favored her mother's presence as more supportive than her husband because "she was there. She's my mom." Another female participant relied on her mother for daily help and transportation during her eight-month homebound suffering. She recognized how this reliance and reconnection with both of her parents, but especially her mother, had strengthened her bond with them, "The best thing is my relationship with my mom, and my dad, but mostly my mom has reached a new level." The other two male participants relied heavily on their mothers for support; one leaned on his mother for her physical care both at home and in the hospital while the other needed more emotional and spiritual guidance from his mother.

Relationships between spouses also transitioned during both acute periods and more chronic suffering intervals. The reliance on the other spouse was crucial to sustain

participants through both phases; one male participant shared his feelings about his wife's support during hospitalization, "I never doubted someone would be there, especially my wife. Without my wife it was very hard. She was a trooper through it all." Some participants noted how their bonds with their spouse were tested more significantly when the suffering episodes lingered for longer periods or were highly stressful. Two female participants who experienced depressions shared how their relationships with their husbands were challenged due to their high level of dependence on them. One of them remarked about her husband's remarkable patience and support for her:

My husband, even after we figured out that I was depressed and the counselor affirmed that, he let me work through it. He let me be depressed. He didn't make me feel guilty or pull yourself up by your boot straps, get over it. He let me go through the process of healing and that was so wonderful.

She needed the time and space he gave her to go through her depression without pressure from him. The other participant recognized how much burden her husband carried and how it was impacting their marriage:

It has been more on my husband, he has been overburdened. He has a high stress job, a sick wife which he doesn't know if I'll be up that day or I'll be in bed crying. He basically has to run the house and do every chore and everything. We're not partners anymore. I think that is part of the hard part of it being so long.

The recognition of how much suffering interferes with marital relationships may be under-estimated while she hinted at how her depression exerted extra demands and multiple stressors on her husband, and also threatened their intimacy.

The role of how children offer support to their parents who suffer did not emerge in a significant way, although several examples were shared. Examples offered by participants all indicated a tendency to shield children, based on their age, from the brunt

of suffering, or a need to hide either the suffering or its devastating impact from them. Any reference to children indicated their full support for their parent, but no adult reported a reliance on their child for their primary support. They tended to look to their own parents rather than expecting their own children to provide for their various needs during suffering.

Support from friends. In terms of supportive care offered by friends, simple gestures were once again valued, including meals, short visits, and prayer support. Several comments indicated just how helpful particular actions were for those who suffered, as one participant shared about her husband's hospitalization, "Waking up and seeing all my friends gathered in the room. There were people there who were my friends. Not gifts or cards, but their presence there. People were there praying and caring." Another male offered, "People would come to visit me. Many people sent cards, letters, and e-mails. They would come and visit me in person, offer up prayers and support. That was also a huge support." Prayers and visits from friends were very meaningful, but friendships were also tested when some friends abandoned them or failed to connect with them in their hour of need. One person offered more specifics about how her friends helped her through long months of suffering at home:

I have found there are friends who really mean what they say. One girlfriend who doesn't bother to say what do I need, just gets my schedule when my husband is gone and then goes through and figures out what I'll need and tells me she is doing this and this for you. I didn't realize she cared so much about me.

Her amazement at the depth of long friendship was also balanced with how new friends could also step in and be so supportive, "Even people I haven't been close to have given a meal or a phone call."

Ineffective Support and Care from Family and Friends

Very limited information was divulged by participants during the interviews related to a lack of support from family or friends. There was a major sense of gratitude and loyalty for all that their family and friends had done for them through the trials of enduring and suffering. Two incidents shared offered more information about the lack of friends' sensitivity and the significance about how friends responded in times of crisis. The first example noted how one couple felt abandoned by their friends following one initial gesture of help:

It was weird. We belong to a church and we were in a big Sunday school class. They all signed up for meals, they prayed with us. The pastor came, and the assistant pastor came the day of my surgery because the pastor was out of town. They brought meals and we never heard from them again.

This sudden break in support was not forgotten and was disturbing for the couple in the midst of their own struggles. Another example related how a close friend's attempt to support a suffering participant was received as insensitive:

I do remember one thing that wasn't supportive...I broke down one day and it happened to be at a seminar we were both attending, so I left and went in the hall or something. I don't remember exactly what she said, but the gist of it was that you need to get over this. And I just felt like 'how?' Do you just stop feeling?

The friends' words meant for comfort were not comforting, and closed the door for the participant to share her feelings.

Care and Support from Professional Caregivers

Effective professional care and support. All participants offered feedback about professional care and support when posed the interview question, "How did professional caregivers help you through your suffering?" Their feedback about health professionals, focused primarily on nurses and physicians; offered information about supportive

character traits or attitudes exhibited by health professionals; specific caring actions by physicians and nurses that met their individual needs; and additional recommendations for supportive care they felt may have been beneficial for their individual situation.

Explicit and varied details were offered about professional caregiver character traits and attitudinal qualities that suffering individuals and their family members most valued. These traits and attitudes included, but weren't limited to being dependable, sensitive, personable, approachable, knowledgeable, respectful, credible, upbeat, positive, and honest. Professionals were viewed as more credible if their own lives had been touched by suffering and they portrayed a heightened sense of awareness and ability "to be of help to other people." One description of a surgeon's supportive attitude stressed a calm and deliberate demeanor, "There was something about him. I felt much calm. He didn't rush and took his time. He didn't seem cocky. I sensed a more settled surgeon."

Specific supportive actions comprised the majority of participants' discussion. A male participant stressed how actions were so much more important than what was said as he stated, "I remember more about what they did than what they said." The common supportive actions that were shared were relevant for all health professionals, but physicians and nurses were once again singled out. Participants offered a long list of valued actions applicable to their physicians. One couple mentioned how they really appreciated one physician who prayed directly with them during an office visit and prior to surgery; and how another surgeon talked about his in-depth research about surgical treatment options. The wife also mentioned her appreciation for the physician's regard for their whole family, not just her husband, "Some doctors asked if I was OK and said, 'We don't just take care of the patient, we care for the family. It meant a lot to me.'"

Another participant also acknowledged her appreciation for her physician's regard for her family and how he continued his contact and support to foster hope in her search for a diagnosis as she spent months navigating through multiple referrals to specialists. She shared how comforting his words were when he reassured her and her family, "We are going to find an answer." She knew that he had not abandoned her as she offered, "If I didn't have him telling me that, I would have given up a long time ago. But he gets all the reports, and all the tests and everything."

Comments shared by participants were specific to nurses' supportive actions, and conveyed a closer, more intimate relationship than was experienced with physicians. This more intimate bond and their nurses' recognition of their individuality was described by one male participant who experienced multiple hospitalizations:

I generally got the same nurse every day. There was more continuity there. You got to build some rapport with your caregiver. And they could track your progress from day to day. They had more in-depth knowledge about me and my particular situation.

Two other participants emphasized their appreciation for continuity and a more holistic focus. One talked about his experiences with a nurse coordinator:

She was very caring and compassionate. She would come and visit from time to time. Ask about things and try to explain things. She was very proactive...she probably offered that continuity...the only person who mentioned depression or my emotional state of mind throughout this whole ordeal has been that cancer coordinator.

An additional participant offered his comments about supportive nursing care, based on

his experiences during several hospitalizations:

There were a couple of nurses who did more than other nurses. A couple stood out. Took the extra time to see what was going on. They would check back with me to see if what they did had helped. That was a big uplift to me. They were making an effort. I was always trying to get hope, to grab anything positive, any positive to make it OK. If they felt a positive change and told you that was big...they would talk about little improvements, acknowledge I was not just another patient there.

Hope-building behaviors were appreciated in addition to evaluative checks with the participant to validate helpful nurse actions. He also valued humor which he said “made a big difference, a big difference.” He had a test for his nurse to check their humor and he said, “You could almost tell who would be a good nurse or not by who would chuckle over that, or say ‘oh’ and go on.” These nurses recognized how his humor distracted him from what was going on and what he couldn’t control.

Additional support that participants wished had been provided would have been more peer support options, even online chat groups as one alternative for persons seeking elective surgical options based on a high genetic risk for cancer. A desire for more well-trained staff members and more favorable staffing ratios were also desired to enhance supportive professional care.

Ineffective professional support and care. Participants were interviewed to learn what professional caregivers failed to do to or what they did that wasn’t helpful for them (see Appendix A). The intent of the researcher was to foster a greater awareness of suffering persons and their family to further enhance professional interventions for those who suffer. Participants were at times reticent to disclose these issues during the interview. Their reluctance may have stemmed from feelings of disloyalty or ungratefulness for their caregiver’s support, but they also expressed a desire to foster

future care improvements by health professionals. Professional caregivers, particularly some nurses and physicians, were identified by participants who failed to offer supportive care. Names were withheld during the interview process to protect specific caregivers' privacy. A generalized summary has been offered to expand one's awareness of this highly sensitive area. Participants' concerns related to ineffective support and care focused on three main areas: lack of professionalism, failure to recognize or acknowledge needs, and a failure to provide adequate information.

Lack of professionalism. The first area of concern expressed by multiple participants was an occasional lack of professionalism during their interactions with health professionals. Examples of unprofessional conduct ranged from apathy, scolding patients and families, discriminatory ageism, to extended delays and waits during care. The contextual and circumstantial elements were discussed for every situation.

Examples of health professionals who exhibited apathy were noted by half of the participants. Apathy was noted as a lack of regard for sleeping patients and families when lights and loud voices disturbed their sleep; confusion in knowing individuals even after long hospitalizations, and task-orientation without attempts to even speak to the patient in the bed. One person described the attention to tasks as, "They would come in and do their rounds. Some would be a little more caring than others. Some would just stick to their work, run your rounds." Another family recalled having a resident physician come by on rounds to review charts, who didn't enter the room when the participant was very ill. The family overheard the resident talk about bright red blood on the phone. When the family asked the nurse when the doctor was coming, the nurse stated that he had already been

there. The nurse did call the resident to ask him to return to share a condition update, but only after the family requested it.

One family experienced a resident physician who scolded them, “one of the residents fussed at me because I changed surgeons.” Another participant’s father, who was hospitalized several days after a debilitating CVA, experienced potential ageism when his physician denied him any further rehabilitation options. The son recalled the conversation with his father’s physician:

We’re not even really going to have him go down to therapy. Your dad’s really just gonna be staring at the wall for the rest of his life. He said there’s just too much damage. He can’t even sit in a chair and hold himself up to wait to go into therapy, so I don’t even recommend therapy.

The family checked their father out of the hospital and he was treated at a rehabilitation center that specialized in brain injuries. A year later the same physician saw the father and couldn’t even recognize him due to his improvement as his son replied to the physician, “You know you gotta be careful what you say to people.” This lack of professionalism hurt the father and his family by adding further to their stress and concerns for his well-being, but also prompted them to find appropriate therapy for their father.

Failure to recognize or acknowledge needs. A failure or insensitivity to recognize or acknowledge participants’ needs by health professionals was frequently reported, but particularly affected those persons’ whose suffering was prolonged with longer enduring phases. Their comments focused on the three areas of concern: a failure by professionals to listen and respond to expressed needs; inattentive care; and a lack of holistic focus and assessment.

A failure to address participants' needs was common to most participants at some point in their journey of suffering, and was often linked to extended delays and long waits with infrequent updates during the diagnostic or treatment process. One family waited from 7 p.m. to midnight before getting to a hospital room during an emergency room visit. Their frustration with this experience was based on the lack of communication. They sat in an exam room two hours before seeing a nurse, no one came to check on them, and no one offered any updates. Another person waited 30 days to get an appointment with her surgeon when she was experiencing excruciating pain. She struggled to self-treat her pain as she waited for help:

I couldn't get past his receptionist. I couldn't have his (surgeon's) ear...They wouldn't take me and so I used my own pain medication, anti-inflammatories, which I take all of the time anyway and I just toughed it out until my next appointment. So it was 30 days in between my first appointment and second appointment. I did suffer and I was really impacted by that.

Some of these delays may have been unavoidable, but professionals failed to acknowledge how these delays impacted persons who were already suffering.

Some situations revealed the vulnerability of persons who struggle and so desperately need to be heard. Failure to listen and respond to expressed needs was life-threatening for one participant:

I kept trying to tell them the pain is getting worse by the second. It took until I was flipping out that finally they decided to do something...I wished they had listened to me from the very beginning, that there was a problem, that I was suffering. My suffering was getting worse at a very incredible rate; I wish they would have listened to me at that point.

Another participant was shocked when he was discharged before he felt he was ready:

I was flabbergasted. I couldn't believe it. I wasn't able to eat properly. I had a probably a 5-6 inch open abdominal wound. I couldn't believe they would just send me home like that. Especially since everything didn't feel right, with the open wound and everything.

He ended up having to return to the hospital, but he said, "it took a weeks worth of calling in to the doctor. Them saying you have to eat. Trying to be a good scout and follow directions. The whole time everything was just backing up on me." He felt that his needs had not been recognized, delaying his recovery even further.

Inattentive care was experienced frequently by many participants. This was often blamed on professionals' inattentive presence or busyness, as one person shared, "for the most part, the nurses were so busy. They were in and out of there really fast." Another description of this inattentive, and sometimes frantic interaction, alluded to the desensitization to needs by nurses who saw so much suffering that they lost sight of what suffering meant to the patients, "No, they see so many people with so much suffering going on. I guess the busyness of their job is not conducive to sit and hold your hand."

Finally, a lack of holistic focus for suffering persons' needs was noted.

Professionals offered very little engaged assessment or discussion focused on the psychosocial or spiritual impact of suffering. One participant repeatedly commented about this deficit, primarily the emotional trauma with suffering:

Somewhere in all the medical professionals I dealt with, all they ever concentrated on was fixing the cancer. Whereas, if you're looking at the overall picture of suffering it is more than just that, it is your emotional state of mind. It really makes a big difference.

He was frustrated with this omission and felt that too much emphasis had been assigned to the cure of his cancer rather than the care.

Professionals do not offer enough information. One of the most prevalent omissions in most participants' contact with health professionals during their suffering was the lack of information, or the interpretation of information relevant for their personal understanding and personal application to their own experience. The participants offered feedback regarding the unorganized process of dissemination of information by health professionals not tailored to their individual needs for information during their suffering. Participants related how disturbing and stressful the unknown was for them, from waking up after surgery not knowing what happened; to how to care for themselves and interpret their pain and recovery process on their own. Their needs for information focused on learning how to cope with the confusion and the disorganized educational processes; the need for advance preparation; the critical timing issues for information; and the need to learn and interpret "normal" cues for pain and their recovery progress.

General feedback was shared about the confusion and disorganization of educational processes which were implemented by inter-disciplinary health professionals that were encountered during their suffering. There was a lack of awareness of their individual needs and personal health history based on the varying educational levels and the revolving multitude of health professionals they encountered in their use of health services. One person said, "I tried to listen to the multitude of doctors, every day a different face in front of me, explaining what was going on." Another person offered his perspective, "Every shift nurse would come in and bring a different personality, or a different level of knowledge of my particular background. Sometimes I'd get the same nurses for a few days in a row. They would have a little bit of insight as to what my particular history was." Feeling like professionals knew them as individuals, particularly

their history and current condition, was vital to them, but was often lacking in consistency.

A need for anticipatory advanced preparation was noted based on the threat of the unknown which added to participants' suffering. Information was highly prized by many individuals, and a means to support endurance of intense pain:

Information more than anything, especially when I was feeling all this pain...being in intense pain, understanding what was causing it and why it was happening. It wouldn't have made the pain any less, but it would have made the suffering less. You would have known what was going on, that there was going to be an end to it.

Another participant reinforced the extremely vital role that information and updates were for them, "Just taking the time to explain what was going on more than anything else. That alone made more of a difference than anything else." It was very important to have frequent and very specific progress reports so that they were updated on any changes in their condition or treatment plans. They also appreciated being empowered to make the care decisions that fit for each individual. There was a great need for professionals to "acknowledge what you're going through," and not make assumptions that they knew one's overall experience.

One person commented, "The whole unknown aspects of it just really intensified the suffering." Knowing what to expect was mentioned often as a concern, "The first time around, it's all blind when you walk in. No way to predict what happened." Other issues that surfaced related to unknown aspects of care included the need to learn how to judge the pace of recovery; learn about medications and their side effects; and all other issues involved in the selection and execution of plans of care. More depth and details with information along with advance preparation was desired as one person declared his

feelings and a desire to have more control in his situation gained through knowledge:

Being able to know that stuff ahead of time wouldn't necessarily make it easier, but it would maybe had made me understand a little bit more about what to expect and to understand and have a better insight. It would have allowed me to set more reasonable expectations for the pace of my recovery. One thing that caused probably more frustration than anything is just being completely helpless to change anything about the pace of my recovery.

Another issue shared by another participant was her need for further clarification to help her understand her treatment options which she obtained when she pressed for more information, "I need to see my MRI [Magnetic Resonance Image]. I need to know exactly what's going on with my knee. And he was rather startled. It was like nobody had ever said that before." The physician arranged for her to review her MRI with him and she recalled, "That's exactly what I needed."

Timing of the information shared by professionals was important including information related to the sequencing of the care received and having information "just in time" rather than too far ahead or not before it was desired. One person explained, "There's a lot of stuff they don't explain to you beforehand. How things were supposed to work after the surgery." Even if advance information couldn't be shared, professionals need to realize that there are emotional consequences when persons can not be prepared in advance for unknown outcomes. This was related by a participant following one of his surgeries, "They ended up going in and doing a lot more but I didn't know that until I woke up...the shock and being awake and finding out they did a lot more than what they planned." Emotional support for not knowing and learning disturbing news along with repetition of information may be just as important as the actual information offered.

Finally, one additional aspect related to the need to learn more about how to discern “normal” pain cues and their relationship to one’s overall recovery. Several participants offered their concerns while one shared these comments about “normal” pain cues:

I didn’t know what was normal. I didn’t know that the pain I was feeling was right or wrong. Even now after this (recent) surgery, I’m going through pains I’ve never experienced before. I’m wondering, is it a good or healing pain? I’ve had nothing that’s more than recovery pain. That is frustrating. It is frustrating because you don’t know the first time you’ve had this, what is right or wrong.

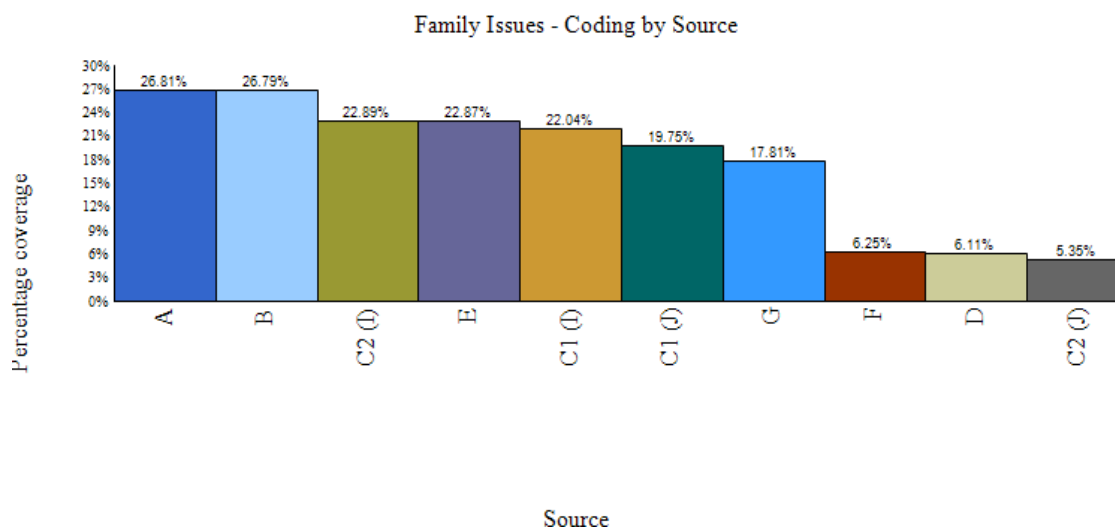
Anticipation and education about the expectations of the overall pain experience during recovery may have been helpful, or possibly having someone with which to check back during the weeks of recovery prior to the surgeon’s follow-up visit may have given the participant more support after discharge.

Family Issues

The fourth most frequently emphasized theme, family issues, was covered by a mean of 17.7% interview coverage, slightly trailing the theme of care and support. Two participants tied in their emphasis of coverage for this theme with 26.8% of their interviews (see *Figure 4.4*). Both of these participants shared extensive information about their family’s crucial role in their personal support for their own suffering ordeal as well as other key family members who suffered and/or died during the same time frame. One of these participants had witnessed the death of several close family members due to cancer. Her sister had died during the participant’s recovery from surgery, possibly contributing to her desire to discuss family issues related to these traumatic family events. The other male participant also shared how key family issues had contributed to further suffering in his own life due to his father’s debilitating stroke and his need for extensive

personal care, his mother's struggle to care for his father and her own death due to neglect of her own health, and his brother's alcoholism.

Figure 4.4: Major theme: Family Issues, Percentage Coverage Coding by Source



Note: All sources, labeled by letter reflect interview sources with the exception of two journal sources (J) by two participants who were also interviewed (I).

Overall specific family issues imposed by the suffering included the impact of decision-making on families, a sense of powerlessness, parallel suffering, the need for unconditional love from family members, and resulting family tensions.

Decision-making in Suffering and its Impact on Family

Participants' suffering elicited the need for vital decisions which had a significant impact on their family life and relationships. Key elements of the decision-making process discussed by participants included the need to seek opinions or consultations prior to finalization of choices and the need for affirmation of their choices by families and health professionals. Autonomy and self-advocacy in this decision-making process

was prized by some participants while others turned to their family for help with decisions. Once a decision was made, the participants also struggled with acceptance of their decisions.

One participant considering her surgical options for a bilateral mastectomy and oophorectomy, based on a confirmed genetic predisposition for breast and ovarian cancer, related how these decisions really comprised a majority of her suffering. She made her decision based on thorough research and one surgical consult and was confident in her choice and did not desire a second opinion prior to her surgeries. Despite her ability to understand the literature and information and what appeared to be “the ease” of her decision, she did appreciate the validation of her decisions. She relayed how helpful it was for her decisions to be affirmed, “It was different with me. A lot of people are dealing with chemo after they find out they have cancer. They always complimented my choice. That it was a good choice.” Her father also affirmed her choice for boosting her survival chances by moving ahead with the recommended treatment, “My dad was like, I hate to see you have to do that, but I’m glad you did with every female in my family that was dying of cancer.” These affirmations of her choice seemed to be very important to ease her suffering caused by such difficult and life-impacting choices.

Another participant and her husband agonized over steps in the diagnostic process and the need to consult with more than one specialist due to the complexities in her case. She expressed her desire to avoid criticism for her decisions:

I feel obligated to finish the course that they’ve set. Then they said we’ll refer you. I don’t want to go, but don’t want anyone to say I didn’t try everything, that I cut it short. I want it to be I did everything I could.

Her frustration with her lack of autonomy was evident.

Decisions tended to create more tension and strain in relationships than at first was realized. Though persons who suffered desired their family's input and support, they also valued their autonomy and often their ability to self-advocate. One participant relayed his mother's need for autonomy at the end of her life when she got cancer. She chose not to be treated and died. She struggled to tell her husband, but left it to her son to do so. Her son recalled her saying:

You know I'm 82, quality of life is everything. I know where I'm going, Doc, you don't have to feel bad for me. I'm choosing not to have treatment. I said you know I'll die in four months and if I die in four months, I'll have four more months of quality living and that will be it. Watching her make her own decisions like that; I don't know that I would have changed a thing or done anything differently...that's what she chose to do.

Her rationale for her decision she made for herself was based on quality of life over her family's dependence for her to survive.

Other participants tended to lean on the advocacy efforts of their own family members or friends while some sought professional advocates to guide key decisions during their suffering events. One male participant leaned on his wife to make his decisions, especially those regarding complications during and after surgery. His wife recalled how difficult that was for her, "He left all the choices up to me. He would never say no to any of those surgeries." Her husband validated his support for her decisions, "I knew she made the best decision possible and I knew she would." Nurses were also helpful for his wife during the times when she was forced to make decisions were needed. She found the nurses' guidance and encouragement for her to consult with different physicians for a second opinion very helpful during her times of indecision.

The acceptance process for decisions and outcomes proved to be significant in either helping to overcome struggles due to suffering or further extending persons' levels of suffering. Participants vacillated in two directions; some persons were able to move on with their lives without self-doubt and second guessing:

Once in awhile I would play the game in my mind. I said just forget this. I couldn't go back. I was like, no...because if you're not going to do it, every six months you go for a breast MRI... More CA-125 testing and some things they recommend. And it sounded high maintenance to me. I couldn't back out. And plus worrying, I'm sitting there waiting to hear, now you do have it...I just thought I can't go back through that frame of mind. I made my decision, I'm beyond that.

Several persons continued to re-evaluate their decisions, especially if the outcomes of their struggles were less desirable or delayed by complications. They tended toward regrets including doubts, guilt, fears, and the feeling of burdening their family members.

This tendency for regrets resulted in escalating family tensions. One participant shared:

"...to know he'd gone through all this because I made the decision to take part of his colon out. They'll always be there, the guilt I feel [tearful]. I feel guilty with that burden. It always comes back when he has to go through one more thing...I didn't trust my gut instinct to postpone the surgery because he [physician] assured me it'd be OK. I listened to the doctor and regretted it."

These doubts and regrets lingered to impact their marital relationships for years following these events.

A Sense of Powerlessness Impacts Families

Powerlessness, often expressed as fear and self-pity, was common with all study participants and their family members. Events that contributed to this sense of helplessness in the face of suffering included the demands impacting both parties in the face of their struggles, a sense of burden, and the realities of living with suffering. Facing

the realities of living imposed by suffering forced family members to leave their loved ones to continue working and upholding as much of the family load as possible. The frustration of balancing these additional demands placed on one participant by her husband's prolonged suffering was expressed:

No, no, that was hard going to work and leaving him up there. My mom had been here and she was helping but she had to go home. I had to go to work. To know he was suffering. Towards the end I would work in the morning and spend the night up there. He would be kind of OK in the morning and when I came back at 5 p.m. he would be so sick again and I would feel guilty. I had been gone and didn't know what to do for him.

The torment with leaving her husband and finding him in worse condition upon her return was agonizing for her.

Family members and the "primary sufferers" within the family units felt this powerlessness in distinct and often unique ways. The primary sufferers expressed feelings of being a burden to their families and rejecting pity from them. The extended burden and this sense of burden placed on family members were expressed by one participant:

Every day was just a struggle, and I guess along with that suffering was knowing what my spouse was suffering. A lot of it was on her own because I was so medicated and was out of it. Just knowing she had to deal with it all the time.

This same participant relayed how he detested putting his family in this position of suffering, yet he didn't want their pity, "I hated my family having to go through this. I hated that part of it, being affected. I did not want that, and feeling sorry for me."

Family members, who were not the 'primary sufferers,' also experienced intense feelings of powerlessness. Family members related these feelings of helplessness as they watched their loved ones suffer while hoping to spare their pain along with the need to

keep up with pressing commitments like work and meeting other family needs. One participant shared how he and his mom felt about her terminal cancer and its impact on his dependent father's ongoing need for care, "Mom was just going nuts, I can't die. Who's going to take care of dad? I don't know, mom, we'll have to figure that out when we get to that." He shared how difficult this was to watch his mother's decline in health, "It was hard seeing her go down, suffer so quickly. And trying to be supportive of her decision [to not seek treatment]." He expressed relief when his mom's condition required hospice care where she was medicated for her pain as he said, "Just to know that she wasn't suffering was a great relief and prevented me from suffering."

Another participant recovering from her own surgery remarked about her inability to help her dying sister's family in another state due to her own disability and recovery, "Mostly I wish I could do something for her family. I just can't." The desire to comfort and ease their loved one's pain was often impossible, "To see him suffer, I couldn't do anything for him. I rubbed his back or feet, sat quietly with him. It was hard because we couldn't touch him because everything hurt. It was hard to comfort him." This sense of helplessness was expressed again and again, "I still feel bad you had to suffer...sitting by her side and watching her hair come out. Watching her go through that was awful."

Parallel Suffering

A definite consensus was communicated that all family members were influenced in some manner by the life-altering suffering experiences. One person shared, "Often the person that isn't going through it would rather be the one going through it. It isn't the one alone going through it." But, it was as if these family members each had their own suffering course, simultaneous situations or encounters occurring, their own distinctive

versions of suffering, unique and separate from each other. This suffering was viewed as parallel or analogous, often with limited intersections with each other as one participant shared: “Yeah, you can just be there for each other, but you can’t feel the same about some of the suffering. They are not feeling what I am feeling.” One participant shared how several of her family members reacted to the series of deaths due to breast cancer in her family compared to her husband’s mother’s death:

It’s just a different form (of suffering). To go through this yourself is one thing, but to not be able to do something for someone else is another form of suffering, I think...I think we’ve learned if I lose my mom, he lost his mom, I lose my sister, you kind of understand. You can’t feel what they’re feeling. You can’t feel their pain, you feel sorry for them. My siblings felt more of what I felt with my Mom. I understood when he lost his Mom that I can support, but I can’t feel what he’s feeling. We’ve learned to support each other.

Each person in this grieving family had their own unique grief experience and each needed understanding. Assumptions that each was feeling the same would be inaccurate and not a source of comfort to them.

One additional influence on the family was the desire to shield family members from the brunt of the toll of this parallel suffering. One mother participant expressed her temptation to let her daughter take over for her, but her stronger desire was to spare her daughter’s suffering and preserve her teenage years, “I try to be careful not to expect her to take over for me. It would be real easy to have her take over. She has a full life, and I want her to have her life. I try to be careful to let her be a teenager.”

Role of Unconditional Love from Family

The vital role of family members who offered their irreplaceable and unconditional love and support contributed positively for those who suffer. Participants who hadn’t depended on their own parents for years recognized how much they needed

their own parents' presence and involvement. A male participant offered how helpful it was to have his mom's presence during his entire hospitalization and recovery. Another female participant shared how her relationship with her parents changed as she faced over eight months of disability and incapacity to keep up with her life:

Sometimes I just lay my head on her lap, and felt like, this is my mom. (Crying) And when you're grown up you kind of get past that. But the relationship has become not childlike, but so much closer...I think the good thing that has happened, the best thing happened is my relationship with my mom, and my dad, but mostly my mom has reached a new level.

She also offered how her suffering experiences had helped her to recognize how much her husband loved her unconditionally when she couldn't return that same level of love and support in their marriage:

I've learned how much my husband loves me [Crying]. I don't think you understand unconditional love until you have nothing to give back and there is still love and support. No partnership, not even there to encourage him, and he loves me no matter what, and how much I can trust him.

Another female participant offered how her own adult son had increased his level of sensitivity to his mother's needs, "My son has advanced quite a bit in his caring or his awareness." This heightened sensitivity was also recognized by another participant in reference to her own mother's needs, "It makes me more aware. It makes me very acutely aware that she is pushing and to stop and say how are you? Not how everything else is. She pushes and pushes herself. Sometimes I have to tell her you need to go to the doctor, to say you need help."

Family members also acknowledged their need for continued love from their suffering family members. One mother shared how her teen-age daughter shared how much she still needed her mother's love and guidance, even though their roles had

changed:

I asked her if it bothers her if I'm in bed when you get home. She said, 'I don't need that kind of mom. No mom, I know you have your door opened and I can come to talk to you. What I need is guidance and encouragement and I don't care where you are.'

This mutual love and compassion shared between family members was vital in their journey of suffering.

Family Tensions

Despite the growth in many family relationships, the burdens and stressors imposed by suffering created strain and tensions in these relationships. Concerns and changes in family dynamics arose, the level of trust was tested as different needs for care and assistance from family members emerged, and a wide range of emotions surfaced.

The series of events that coursed through one family before and after their mother's death created changes in family dynamics. Disagreements between the parents and their sons centered on care decisions for the parents and their willingness to accept the help their sons felt was appropriate. The son commented, "You're kind of caught in between and you want to help your parents. They don't want to be helped, don't want to spend the money on it, and not getting dollars' worth. I said, Mom think about how much you're saving by not having dad in the nursing home." Many concessions were made to accommodate their mother's wishes. Following her death, multiple issues emerged, "Yeah, so there were a lot of plates spinning and it wasn't that you just had one thing that you could concentrate on. And that's probably what you find out happens, death sets off a series of events."

Another family was impacted by the wife's prolonged depression over the course of thirteen years. The participant recalled how her husband coped during those years, she said:

My husband would cope by going for walks and he said you were hard to work with because there basically wasn't anybody home. He wondered what had happened to his wife. Neither of us knew where she went.

That lost connection in their marriage relationship, due to her emotional absence, was felt by both of them.

The level of trust between family members was tested as different needs for care and assistance from family members emerged. One participant's mobility was limited which forced her to rely on her son for assistance. This role change was a new situation for her and she expressed concerns, "Can I really depend on him? So that's a concern and of course I have to trust him on that and I have to take the consequences of my decision and he has to live with himself if he doesn't measure up." Both mother and son faced risks in seeking to work out a caregiving plan for her, one risked losing faith in her son if he could not follow through to help, and the son risked losing faith in himself to hold up his commitment to his mother.

A wide range of emotions within families surfaced as they responded to the threats suffering presented to them. One wife grappled with the guilt of her decisions for her husband, "That will always be there, the guilt I feel (tears). I feel guilty with that burden." Grief experienced due to the deaths of a mother and grandmother due to cancer impacted one participant who grieved the loss of role models for mothering. She expressed how that loss of her own mother impacted her own relationship with her

daughter and she didn't want that to happen to her daughter if she died from cancer:

I didn't have a role model...I didn't have anybody to correct me. Maybe I was hard on her (daughter). Grandmas have the unconditional love. My husband lost his mom so they don't have any grandmas to be a buffer, a role model. I didn't know I didn't have a role model until now as I'm older. I would have acted differently.

Focusing on lost role models seemed to be a way to express her grief and how her own mother's presence in her life may have altered her own nuclear family today. Another source of family regrets due to suffering's impact was related to the impact of hiding it from the children. A participant who experienced a prolonged depression for many years worked very hard to maintain an image of normalcy as she remarked, "I'm not sure I let our kids see what was really going on. I kept it from them." Keeping her pain hidden from her loved ones minimized their ability to understand her and support her.

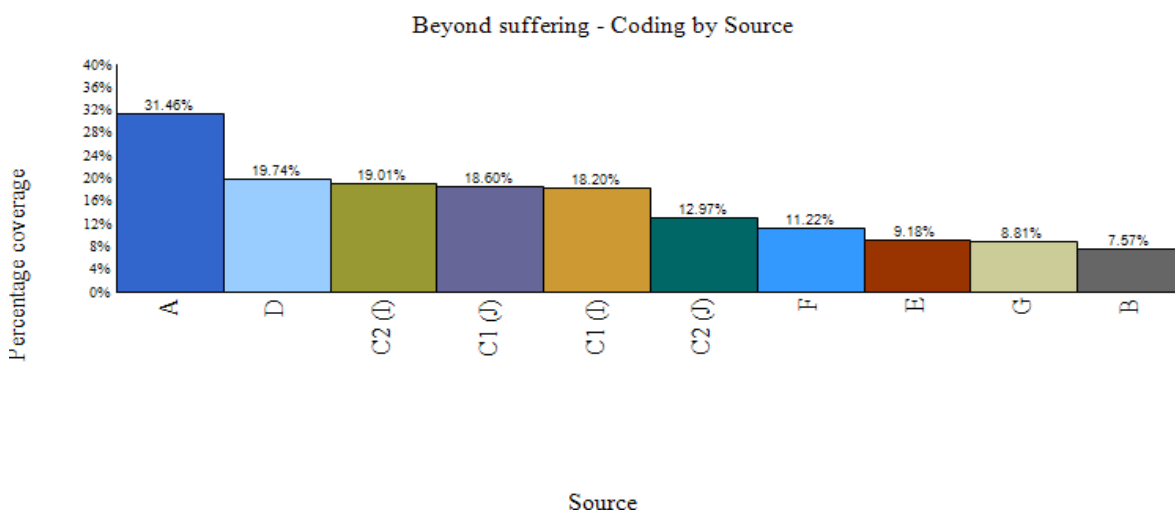
Beyond Suffering – Recovery and Healing

A fifth major theme, moving beyond suffering and its life-impacting influence toward recovery and healing, was challenging and often limited by many variables. In response to the primary interview question, "What are your perceptions of healing at this point in your experience of suffering?" (see Appendix A), participants revealed stories of healing focused on primarily, gradual adaptations to physical changes resulting from their suffering. Some anticipated or had experienced nearly complete healing while others' expectations did not include the anticipation of a full recovery. When each participant was asked what they had learned about themselves through their suffering, each person had little hesitation to offer how their self-perspectives and the view of their world had been altered. This changed perspective beyond suffering was a significant and powerful

part of their story of suffering as they offered accounts of adapting to changes during their recovery and healing process.

This desire to talk about life beyond suffering toward recovery and healing, was slightly lower than the third and fourth-ranked themes (mean of 15.7% interview coverage), but was clearly the least-ranked of five themes (see *Figure 4.5*). One person exhibited the highest focus on this theme with 31.5% interview coverage, with the lowest interview coverage of 7.6% (see *Figure 4.5*). Adapting to changes and alterations in self-perspectives were primary sub-themes for this theme, beyond suffering.

Figure 4.5: Major Theme: Beyond Suffering, Percentage Coverage Coding by Source



Note: All sources, labeled by letter reflect interview sources with the exception of two journal sources (J) by two participants who were also interviewed (I).

Recovery and Healing - Adapting to Changes

As participants reflected on how they were adapting to changes resulting from their suffering, varied healing approaches and coping skills were offered. Some persons

expressed personal goals for themselves. Some had gained a motivation to resume or incorporate self-care. This motivation to take charge of their healing contributed positively to their recovery. Others realized that they may not return to their normal state of physical health, but possibly a new normal. For a few persons, the new normal was a bit better, but for most the new normal meant change or loss, requiring significant physical and emotional adaptations. Adaptations or issues related to the physical healing process offered by participants focused on the identification of their own interpretations of benchmarks to measure healing along with their issues of coping with pain and discomfort. Emotional healing issues focused on battling depression and other stressors and worries, such as financial strains due to the disability imposed by their suffering.

Some persons expressed goals for physical recovery for themselves. Some offered their motivation to resume or incorporate self-care. One participant, who had been required to leave work after his first return due to complications, offered his recovery goal, “My priority is I want to be as healthy as I can be before I start back into work. I don’t want to go into work and bow out and come out again.” Another participant shared the positive results of his self-care regimen:

I’m still on heart medication, things like that and vitamin supplements and fish oil and a lot of different things that go along with that to help boost your good cholesterol and lower your bad cholesterol. My last cholesterol readings were fantastic. He (doctor) said I can’t believe it.

He realized the ongoing nature of his healing and the self-care it required to maintain his health for years following a myocardial infarct.

Several persons shared their adjustment to a ‘new normal’ state of health. One person’s comments reflected how deeply the impact of suffering lingers, “Physically,

suffering has affected life a lot. I'm still suffering and shows how much pain I had before. Sometimes it is easier to get through because it is nothing like it was. Comparing a band-aid with a cast." A reference to a changed future with a 'new normal' was offered by another person, "Normal might be a different place now than it was before my surgeries." Recognition of the need to define a new normal, particularly with pain management issues, was further described as:

I don't think I'll ever be completely like I was before. It just won't happen...I have a fear I'll have this for the rest of my life. I know I'll never be the person I was before the surgeries, but I want to get back to a half-way normal level. I know I'll still have pain, but if I exercise at least and do thing to help counteract that pain, that is what I want to do. I want to control the pain and not have the pain control me.

Despite the need for physical adaptations imposed by new limitations, all participants appeared eager to advance towards recovery and healing, despite the changes and unknowns that might be in their future.

One issue with physical healing involved accommodation to the pace of recovery, as persons noted variations in their rates of healing and coping with issues of pain and discomfort. One participant offered a detailed account of his perceptions about significant benchmarks or milestones in his healing process:

The last couple of weeks, I've finally been able to see some measurable improvement. Not measurable so far as so many percentage points, but where I can feel it. Getting rid of the bandages on my incision was a kind of mental block more than anything else. I did not want to start back at work with still having bandages on. But I've started gaining some weight in the last couple weeks...I couldn't gain weight to save my life, but finally within the last two weeks, I have been able to put on a couple pounds, maybe five pounds or so.

This participant was closely monitoring his weight gain and found the removal of all bandages to be a significant milestone for him.

Issues of pain in suffering continued during this adaptation period, some persons did not know if their pain might continue to linger in their lives on a long-term basis. There was recognition of how one's pain had changed, but the cues were different and confusing for several participants. One person offered his struggles with pain following gastric surgery:

It's like when you have stomach pains and you are hungry, for example. I'm still trying to get used to the kind of pain I have now. It is different than what I was used to. I don't know if the pain I am feeling is right, if it's hunger or if I've overdone myself. I don't have the exact pain I used to have. If I get something and eat and I still don't feel good, what is the pain?... I have to learn my cues all over...the healing process, my body is adjusting to all of that.

Distinguishing between different types of pain and relearning hunger cues were all part of his adaptations in the healing process. He summarized his thoughts about pain and healing, "I want to control the pain and not have pain control me."

Long-term emotional healing issues included lingering depression and other stressors, such as financial strains due to disability imposed by their suffering. One participant sought counseling and noted how helpful it was to hear from his counselor that depression was to be expected after his ordeal:

Of course you are depressed, you have been through serious trauma and other emotional events in your life from the past year. Who wouldn't be depressed? There is nothing wrong with you. Maybe what your family members need to do is just understand it is not unnatural to be that way as your body starts healing up and as your discomfort lessons, your mood should improve with it.

He expressed how helpful it was to hear that depression was a common occurrence following the type of suffering traumas he had endured. He gained a sense of hope hearing from a health professional that it was also likely to be a temporary or situational depression.

Another participant discussed how her recovery process took time, following years of depression. She was thankful for her husband's support for this, "He let me go through the process of healing and that was so wonderful." She recalled a time of experimentation with the omission of her anti-depressants after she started to feel better and said, "And then thinking maybe it's fixed now – wanting not to be dependent on the medication. Probably a matter of pride because I'm healthy now, you know, but I'm past that now." She was able to feel and recognize this emotional healing, "Yeah, little by little. I don't know if I would say 50% healed or 70% healed."

One final issue that impacted multiple persons was the finances, linked to the costs of health care and the inability to work during bouts of suffering. One family was forced to live on disability pay and they also had medical bills, "some demanding full payment." Financial pressures impacted participants to return to work as soon as possible, often before they were fully ready, putting them at risk for setbacks and complications in their recovery.

Self-perspectives After Suffering Eases

In response to the final interview question, "What have you learned about yourself through this suffering," (see Appendix A) each participant offered how their self-perspectives and the view of their world had been altered due to suffering. This was a serious issue that required some additional time for contemplation during the interviews. An altered self-perspective seemed to be more evident to participants after their suffering had eased, when its grip on their life had lifted. Those who had been able to move further away from suffering's influence had more to offer about what they had learned about themselves and others close to them. Their comments revealed the nature and extent of

their suffering's influence on their view of self and life. Shared self-perspectives included areas of thankfulness, blessings, joy, and acceptance; significant changes and growth in self; personal lessons and insights about living; a new or deeper regard for others, even those not so close to them; and a search for meaning or a "why" for their suffering.

One participant expressed joy following the suffering he had lived through, "I consider myself blessed. Fortunate that God has taken some of these areas of suffering and turned them into joy. You don't see it at the time, but look back on it later." Another participant, nearing full recovery, shared her views on acceptance, "I've seen that with people I have worked with at the office. Somebody goes along and something happens in their life and their perspective changes. You almost like them better...nothing predicts what will happen. You accept."

Many participants expressed significant changes and growth in themselves; both emotional and spiritual changes. The participant who supported his mother through death noted how she changed. She was able to accept help that she had resisted most of her life. He said, "So that was a real change in personality, behavior, and attitude, and really humbling for me to see her to be able to accept help because she is a very strong lady." Suffering had softened her and required or helped her to change. Emotional growth occurred for the female participant who also accepted help from her husband, counselor, and family to deal with her long-term depression. She expressed, "One thing that I learned and it really surprised me, was how your subconscious can do things to you without your knowledge and how intricate and interconnected emotional and physical health is and how important it is to be aware of those things."

Spiritual healing and changes were mentioned by at least half of the participants. One person shared, “Spiritually has caused me to grow, for the simple fact that there were moments, I thought, this is it.” His mortality had been threatened and his faith had helped to sustain him. Another older participant offered her insights about spiritual dependence:

I know that suffering is part of God’s design to make us better and more complete and more dependent on Him because we get pretty cocky and arrogant, don’t we? And so, I guess I know that the main part of who I am is spiritual. I know that more all the time but I do get distracted when I hurt. Don’t we all? And so I just know that.

She had grown in the recognition of her spirituality and she was learning a deeper trust in her faith as she shared, “Especially in my faith because you know...some things are exceptional to make us broader and higher and deeper and better.”

Considerations of personal lessons and insights about living elicited discussions of relationships, purpose, some regrets and guilt, and fears for the future. One participant experienced a lesson about relationships, that those close to you don’t always desert you when suffering comes. He offered:

You become a stronger character because you don’t have a choice. I just grew a lot when, especially when she was going through what she was going through, I thought in my mind, I could lose my wife. I’ve lost a lot of people in my family in the past, and to lose one more, I don’t know how I’d handle it.

Another person felt a sense of renewal in her relationship with her parents which reached a new level while another person commented about a new perspective in relationships, “We don’t sweat the small stuff anymore. We are more laid back. Different things are more important. We get along. That’s OK.” Finding a sense of purpose apart from activity and work was meaningful for another participant still in the midst of her suffering as she commented, “God doesn’t really care about what we do.”

An emergence of a new or deeper regard for others and their suffering, even those not so close to them, was noted. The participant who went through years of depression stated, “I obviously have empathy for anybody who has gone through an experience like mine because I have experienced it, so I’m proactive in that way when I sense that a person might be dealing with depression and they may not recognize it. I usually ask them.” Another shared her regard for others as, “And hopefully I’ll be able to help somebody else get through their knothole. It’s all about knotholes.” An awareness related to how others are hurting and pushing themselves grew for one daughter who said, “It makes me more aware. It makes me very acutely aware that she is pushing and to stop and say, ‘How are you? Not how everything else is.’ She pushes and pushes herself. Sometimes I have to tell her you need to go to the doctor. To say you need help.” Finally, one male participant shared it as, “helping others suffer through.” He gained assurance from others around him who believed he survived to help others.

A search for meaning or a “why” for their suffering, was important to some participants. Others conveyed this as their life outcomes to follow as a result of their suffering. One participant, a priest, found renewal in a healing ministry when he asked his congregation to pray for him; he “went from a death sentence to a life sentence on that day.” He offered further details about his perspective for his survival:

God spared my life at 37 with cancer and again at 50 with the heart. So you’re going ‘thank you Lord, I’m still around.’ Maybe this is one of the reasons why, helping people with their dying experience. I’ve gotten over the guilt, because there was a little guilt there for a little while.

Another male participant wasn’t aware of what he’d learned in suffering, he was still

searching:

I have been racking my brains, trying to understand or figure out what reason or what lesson I was supposed to learn from all this. It has been a pretty brutal lesson in acceptance and patience. Aside from that, I don't know if I subscribe to the belief everything happens for a reason.

An elderly female shared how her suffering offered her a deeper life experience:

I'm sure it will be. You know when I get on the other side of it (suffering), I don't know if it's going to somebody I meet in the hospital or just one my friends that ministers to me or my son or whatever, but I know there is going to be an 'Ah ha!' So that's what it was all about.

She was waiting to see how her suffering would either bring more meaning to her life through an opportunity to help someone else.

Results Summary

In summary, the aim of this phenomenological study was to explore the lived experiences of persons who have endured life-impacting suffering events. Qualitative data analysis revealed rich descriptions for five major experiential themes including descriptions for the nature of suffering, the process of enduring, effective and ineffective care and support, family issues linked to suffering, and moving beyond suffering to recovery and healing.

The nature of suffering encompassed many holistic dimensions of living with suffering including emotional, physical, spiritual, and sensory components with common threads and individual variations. Emotional suffering, which emerged as most prominent, was often hidden from loved ones and professionals, and not fully acknowledged or addressed in participant's experiences. Physical suffering, although disease specific, focused on pain issues and limitations imposed by symptoms or surgical processes. Suffering tended to trigger further suffering, a downward spiral followed,

leaving its life-impacting imprint on participants. Persons shared a surprising openness to reveal sources of spiritual suffering as they shared their struggles to maintain a connection to faith and their God to survive threats to their known existence and own mortality. Sensory suffering, represented by hyper-sensitivities to touch, voices, music, sounds, images, and smells, uncovered glimpses of the deep traumatic nature of suffering that permeated one's senses and left an imprint hard to discard from one's reality.

The process of enduring suffering revealed an overwhelming and holistic "shutting down" process of mind, body, and spirit. This distinct enduring state took participants through their toughest moments of despair to a subtle turning point of transition towards survival and recovery. In the midst of these dark hours, persons were often isolated and longed for the help they couldn't ask for themselves. A tender and vulnerable state was revealed as persons emerged from this state, after mobilizing the strength and motivation to 'fight back and press ahead.'

Participants' evaluations of their experiences related to care and support revealed that families tended to offer more reliable support than professionally-based care. Discussions about effective family-oriented care uncovered the significance of daily presence, dependence on parents and particularly mothers, and time and space to heal. Friends also contributed presence and prayers as their actions, not words, were highly valued. Ineffective care and support from family and friends revealed the impact of tested relationships, insensitive communication, and the fear of rejection from loved ones and friends. Effective professional care and support was specified by desirable character traits and attitudes, along with thorough anticipatory attentiveness to their unique needs during suffering and enduring states. Ineffective professional care and support focused on a lack

of professionalism, and a failure to recognize and address needs or offer adequate information to empower those who suffered.

Family issues were impacted by necessary decision-making and how families responded to the sense of powerlessness in the face of life-impacted changes in their loved ones' lives. Additional burdens and stressors created situations of parallel suffering, or side-by-side suffering; where family members existed in their own unique positions of suffering sometimes without intersecting reactions or feelings. Tensions surfaced as the equilibrium of families was altered, with resulting role reversals, trust issues, and varied grief reactions related to losses and guilt. Unconditional love from families was often viewed as a gift to sustain those who suffered. Sufferers were often required to be recipients rather than the givers or initiators of this unconditional love imposed by their vulnerability and limitations.

Finally, most persons relayed how they moved beyond suffering to some level of recovery and healing. This process required overwhelming adaptations to changes and a 'new normal.' Those persons who could acknowledge at least partial healing offered their changed self-perspectives. Outcomes from their suffering experiences noted altered self-perspectives related to views of their former world, stories of joy and thanks for recovery and survival, personal growth, renewed and strengthened relationships, and at times a sense of meaning or purpose emanating from their journeys of suffering.

CHAPTER V: DISCUSSION AND SUMMARY

Introduction

This chapter will discuss the purpose of the study and the interpretation of results with correlation to the literature and the theoretical contexts. A summary of outcomes for each of the aims of the study will be shared based on detailed essence descriptions. A comparison of these essence descriptions with relevant literature and theoretical contexts will be offered to express the meanings and understandings for the lived experience of life-impacting suffering. A discussion of implications for nursing practice, nursing education, and future research will follow.

Purpose of the Study

The overall purpose of this qualitative interpretive phenomenological study was to explore the essence and meaning of the lived experiences of suffering for persons who have endured life-impacting suffering.

Research Questions

The study was devoted to understanding the essence and meaning of the lived experiences of suffering by examining this question: *What is the lived experience for persons who have endured life-impacting suffering events?*

The specific aims of this study included:

1. Describe the lived experience of suffering for individuals who have experienced and endured various types of suffering and life-impacting events.
2. Distinguish between the experiences of suffering and enduring due to life-impacting events.

3. Explore perceptions of healing and alterations in self-perceptions for adults based on the lived experience of life-impacting suffering.
4. Enhance professional caregivers' assessment of enduring and suffering; and discover effective and innovative supportive care for suffering clients and their families.

Discussion of how the outcomes of these aims of the study will be discussed in the interpretation of findings, implications, and future research.

Interpretation of Findings

Theoretical Contexts for Suffering

Suffering leaves an imprint on many aspects of persons' lives who suffer. An imprint leaves a "lasting effect, an effect that remains and is recognizable for a long time." The word, imprint, is synonymous with "impact, effect, influence, reaction, and impression" ("Imprint," n.d.). Two primary suffering theorists who have aligned with this holistic view of suffering's imprint on persons' lives were Morse (2000, 2001) and Eriksson (1997, 2002). Both Morse and Eriksson have devoted years to the research of suffering; Morse in North America, and Eriksson in Nordic countries. They have earned recognition for their comprehensive study of this complex phenomenon of suffering. "Janice Morse has developed a comprehensive and complex theory of suffering from a nursing science perspective. Katie Eriksson has done the same from a caring science perspective in the Nordic countries....Both Morse' and Eriksson's research on suffering is considered as theory" (Foss & Naden, 2009, p. 14).

Morse's practical theory, based on strong clinical applications, recognized "two broad and divergent behavioral states of suffering: emotional suppression or *enduring* and *emotional suffering*. These states are not only distinct, but also diametrically

opposite; each demands that the person be treated in a distinctly different way” (Morse, 2001, p. 50). In her *Praxis Theory of Suffering*, Morse developed a theory of enduring attained through an inductive research approach, with a more comprehensive understanding of suffering. She relied on observing behavior but also explored concepts of enduring and suffering through narratives, demonstrating a more multi-faceted approach to research of suffering (Foss & Naden, 2009, p. 17). Based on the dominant emergence of emotional suffering, Morse’s theories of emotional suffering and enduring offer strong support for the findings of this study.

In contrast, Eriksson expressed “the ultimate purpose of caring is to alleviate suffering” (Lindholm & Eriksson, 1993, p. 1358). “In order to alleviate suffering and offer comfort, nurses must see the patient’s suffering in a deep sense from the patient’s perspective as a unique human being” (Eriksson, 1997, p.11). Eriksson emphasized substance more than method, and used qualitative studies as a primary tool for the development of terminology (Foss & Naden, 2009, p. 17). Lindholm and Eriksson (1993) stressed, “the ability to face suffering is not based on an understanding of why, but on the courage to perceive the actual feeling” (p. 1357). A reliance on courage was vital as they encouraged, “the most important thing is to be brave enough to face suffering, to walk straight up to it or right through it” (p. 1360). Eriksson’s emphasis on the individual’s lived experience of suffering and her focus on the courage to pursue the feelings of suffering, validated support for the outcomes of this study.

Morse offered a unique viewpoint in her theory of suffering with the recognition of the distinct phenomenon of enduring within suffering, a primary focus of her research

on the theory of suffering:

Enduring occurs as a response to a threat to the integrity of oneself. It occurs when one first recognizes the threat as real, and it results in a shutting down of emotional responses while the person ‘comes to grips’ with the situation” (Morse, 2000, p. 2).

This shutting down was stressed as the most common theme for emotional enduring, however participants also offered holistic accounts of shutting down physically and spiritually as well. A key postulate of Morse’s theory was her emphasis on the paradoxes of suffering and enduring behavior:

Because of the response of others to suffering (i.e., suffering signals distress, which motivates others to assist), we describe emotional suffering as an external or public state. The nature of the distress and the type of behavior signals present communicate the severity of the distress and place the responsibility onto others to intervene, to try to alleviate the distress by comforting, by *being there* for the sufferer. The *paradox* occurs because emotional suffering is a state that is communicated, can be instinctively evaluated, and motivates others to alleviate the distress. It can also result in the distress of another. Such is the basis of the empathic response.... The paradox is that whereas its public nature enables others to assist in alleviating the suffering, its public nature also demands that emotional suffering be a *private behavior*” (Morse, 2001, p. 55).

In contrast to the more public essence of emotional suffering behavior, Morse saw how enduring behaviors were considered private business for those who suffer, “Because emotions are suppressed and not communicated to others, we have classified enduring as a private state. Again note an interesting paradox: The encapsulating or blocking of the emotions when enduring (hence making it a private state) enables *public behavior/public functioning*” (Morse, 2001, p. 56). Morse’s views on this hidden nature of enduring and public, yet private experience, of emotional experience validated study findings regarding the isolation and longing for help that participants shared as a significant part of their suffering story. Morse’s views on the paradox of suffering provided further evidence for

the participants' limited focus for public displays of emotional suffering, even during in-depth and private interviews.

Other comparisons made between Eriksson's and Morse's suffering theories revealed how Morse seems to emphasize suppression of feelings as an adaptive condition. Eriksson emphasized "the significance of daring to feel the true feelings of suffering" (Foss & Naden, 2009, p. 15). Morse focused more on the physiological dimensions while Eriksson focused on the spiritual dimensions of suffering (p. 15). Together, Morse and Eriksson gave credence to the holistic findings for the nature of suffering theme established in this study.

Despite participants' limited states of cure from etiologies of their suffering, they each communicated some level of healing and altered perspectives related to their suffering states. These perspectives on healing were supported by Smith (2001). "It is possible to be cured yet not healed, and to experience healing without being cured" (p. 22). Burton (1992) also shared a view of healing as not just a change in circumstances or problem, but a change in one's perspective of the difficulty (as cited by Smith, 2001, p. 22).

This study on suffering and enduring was grounded in caring human science theory (Watson, 1979, 1985, 1999, 2002, 2005; Smith, 1999; & Swanson, 1999). Watson defined human caring in nursing as the moral ideal that is "not just an emotion, concern, attitude, or benevolent desire...it involves values, a will and a commitment to care, knowledge, caring actions, and consequences" (1999, p. 29). Dimensions of suffering and enduring revealed deeply based emotions and participants related how the positive impact of others' caring responses, their ability to grasp the depths and complexities of their

emotions, and their desire and capacity to know their suffering and enduring was vital for them. Others' caring actions demonstrated a commitment to care words couldn't always communicate.

Watson's recent move toward a new term for caring, "Caritas," emphasized a deep form of transpersonal caring and love. This 'caritas' type of caring, primarily offered through family members, but at times matched by professional caregivers, matched the unconditional love and supportive care that helped to sustain participants through their suffering ordeals. The courage of family members and professionals to accept the states of suffering and enduring, freed the sufferers to take the time and space they needed for healing. Eriksson noted the shift to a new client-centered paradigm for caring, "a more authentic, autonomous, and clinically practical form of nursing, has been going on for the last few years" to gain knowledge about the patient's world (1997, p.8). She also defined the basic motive of caring as love; the "caritas motive." She asserts that a "caring relationship forms the meaningful context of caring and derives its origin from the ethos of love, responsibility, and sacrifice, i.e., the caritative ethic (Eriksson, 2002, p. 62).

Swanson's caring theoretical framework (supported by Watson) offered significant applications based on participants' stories of suffering. Swanson defined five

processes whereby caring was manifested:

1. Knowing – striving to understand an event as it has meaning in the life of Other.
2. Being with – being emotionally present and available
3. Doing for – doing for Other what they would do for themselves if at all possible.
4. Enabling – facilitating the Other’s passage through life events and transitions by providing information, validation, and support
5. Maintaining belief – sustaining faith in the capacity of the Other to get through events or transitions and face a future with meaning (Watson, 2005, p. 13-14).

These caring processes demonstrated a close alignment with the caring behaviors participants desired from both family members and professionals. Persons yearned for others to *know* them and their individualized situations of suffering. Particularly during the enduring phase of suffering, they relied on the “*being with*” or presence of family and professionals. They noted the significance of others’ action, or *doing for*, over words in caring responses. *Enabling support* was critical for successful passage through their suffering, during transitions between enduring, suffering, and healing. *Information* to guide choices and affirmation for difficult decisions through *validation* was prized. Others’ *belief and faith* in their capacity to “get through” suffering and to face a future with meaning was expressed in how their self-perspectives were transformed as a result their journey of suffering.

This study has focused on the lived experiences of suffering rather than the etiologies of suffering to enhance the awareness and recognition of the powerful influence the experience of suffering has on the lives of those who suffer. Persons shared how health care professionals often contributed further to their suffering rather than offering recognition and positive interventions. Arman et al. (2004) related in findings

based on a study with breast cancer patients, how health care can cause increased suffering, “patients suffer from the care that has failed to take place and the suffering that has been denied affirmation (p. 253). “There is a tendency among nurses to explain suffering according to what they believe has caused it, rather than describing the suffering itself” (Lindholm & Eriksson, 1993, p.1357). The study confirmed a definite need for enhancement of more in-depth, individualized professional assessments and evidence-based “best practices” for those who suffer and endure with life-changing consequences.

Correlation with Literature

Holistic Nature of Suffering

The initial aim of the study, the lived experiences of suffering for persons who experienced various types of life-impacting suffering, was summarized in this essence description, based on participants’ accounts for the primary theme of the nature of suffering:

Life-impacting suffering presented changes and threats to the sufferer in emotional, physical, spiritual and sensory aspects of life. The impact of emotional threats often exceeded the physical challenges. Pain was often equated with suffering, but suffering was so much more than pain. It was watching your loved one fade before you, clinging to any known treatment or experience, such as chemotherapy because even chemotherapy offered hope, like a security blanket, when one faced the looming threat of death due to cancer. The imprint of suffering also descended on those around the sufferer, its inter-relational nature rippled through families and friendships. Connections with faith and a higher power were weakened as sufferers shrugged off their faith or fought to cling to it, trusting others around them for prayers to sustain them. The senses offered powerful reminders of suffering’s powerful grip on a person; the voices, sounds, touch, images, and smells all connected the sufferer to its reality. It lingered in memories as reminders of the agony and horrors one desperately tried to avoid or dismiss. Despite its power to infiltrate and ravage its victims, suffering hid in the mind, heart, and soul waiting for someone; a family member, friend, or health

professional to come to expose it. But suffering often won, leaving the victims to fight alone, struggling to persevere and endure.

The stories of suffering shared by the participants offered common threads about the theme of the nature of suffering and its life-impacting imprint on all aspects of their lives.

The findings exposed through this phenomenological study reinforced the holistic nature of suffering for the lived experiences of suffering by study participants. Holistic aspects of suffering have been confirmed through prior research (White et al., 2004), but the emotional nature of suffering emerged as the study's most dominant holistic characteristic. Morse (2001) observed how the extensive research about the nature of suffering had been viewed as a response to losses, but it had not previously been considered as an emotional response, using a behavioral-experiential approach. Morse's practical theory or *Praxis Theory of Suffering* emphasized these emotional dimensions of suffering and she designated these as emotional suppression or enduring, and emotional suffering. Carnavale (2009) also supported the shift to emotional aspects of suffering as "attending to suffering in particular calls for a turn towards attending to emotions in general" (p. 181).

Two components tied to the physical nature of suffering that surfaced in this study, but lacked significant documentation of prior study on suffering, included the sub-themes related to how suffering triggers further suffering and the impact of sensory experiences. An unexpected emphasis on the power of the sensory aspects of suffering revealed the level of deep trauma some persons experienced, mimicking symptomology for post-traumatic stress. The influence of suffering and its capacity to trigger further suffering also emerged, based on the chaos and turmoil that resulted from related

complications or unrelated incidents of additional suffering experiences. Both of these areas were shared by multiple participants, yet further study is indicated to explore these particular aspects of suffering.

A strong emphasis on spiritual suffering was evident, though it lagged behind both emotional and physical suffering. The significance of faith became apparent with spiritual concerns tied to suffering that related to maintaining or establishing a connection to God or one's higher power, and finding a sense of meaning or purpose as a result of one's suffering experience. Rahlm and Eriksson (2001) acknowledged the way to spirituality is through suffering and desire. Outcomes of suffering achieved a new wholeness (Fredricksson & Eriksson, 2001) and facilitated the release of painful emotions which brought relief to their spirit (Cutcliffe, 2006b). Gunderman (2002) supported the significance of meaning in suffering, "it's not suffering that destroys people, but suffering without meaning" (p. 43).

The study also emphasized suffering's hidden nature, even from sufferers who may not be aware that their own distress is indeed suffering (Cassell, 1991; Kahn & Steeves, 1995). Frank identified how subtle and difficult it can be to distinguish suffering's existence, "It's what your patients can't say...suffering is the unspeakable...it is what remains concealed, impossible to reveal; it remains in the darkness, eluding illumination; and it is dread, beyond what is tangible even if hurtful" (2001, pp. 354-355). Morse (2001) confirmed this private nature of suffering as one of the "paradoxes of suffering behavior." She showed why suffering is often concealed for many reasons including: "a) if suffering was caused by another, b) if seeing the suffering will make the

other suffer, and c) if the suffering is considered a personal weakness, or inappropriate in the context” (p. 51).

Enduring Mode of Suffering

The second aim of the study asked participants to distinguish between the experiences of suffering and enduring due to life-impacting events. In-depth and descriptive discussions were held about the nature, experience, and effects of the theme of enduring with the intent to capture its distinctions from suffering. Participants articulated characteristics of the unique state of enduring, and related how the boundaries of enduring blurred with their experiences of suffering as summarized in the following essence description of enduring:

Enduring, or getting through suffering, involved the process of ‘shutting down’ to protect the sufferer, to guard that which the person could not sustain or control, in the midst of their toughest moments of suffering or despair. Enduring would come and go. It was most apparent when suffering was intense, or of long duration, or with concurrent or multiple suffering events. Like suffering, enduring was often hidden. People might pull themselves together for a few good hours and then collapse when they were back home or in a secure and private place. Most enduring was short-lived until the sufferer regained strength and motivation for action, to fight back and press ahead. But some persons worked so hard to detach emotionally from the impact or trauma of suffering, effects of enduring still lingered as they resumed their usual lives.

Enduring permeated the body, the mind, and the soul. Physically... it presented with intense and consuming pain, sapping energy and strength so the person could not go any further. It limited concentration and ability to stay awake and paralyzed the voice, shut down the ability to cry, and even eat. Pain could be so intense that it left its victim incoherent, shaking, and feeling like death would be welcome. Emotionally...some felt like ‘nobody’s home, like running into a brick wall, just barely able to function, feeling like something broke, and only able to cope or last minute-by-minute.’ When persons endured they ‘go under, escape, hide, or have no voice;’ Detachment and non-feeling were common reactions. Enduring was isolating, ‘like falling off people’s radar.’ Energy was diverted from interaction when other needs were more critical in enduring. Spiritually...enduring could rob one’s hope and feeling that you’re a significant and cherished person by God and others.

These holistic traits and characteristics of enduring bore strong resemblance to those observed and studied by Morse (2000, 2001) and Morse and Carter (1995, 1996). Enduring was defined as the capacity to last, to get through, or to survive an experience or an intolerable situation (Morse & Carter, 1995, p. 39; Morse, 2001). This unique state was further clarified by Morse:

Enduring occurs as a response to a threat to integrity of self. It results in a shutting down of emotional responses while the person ‘comes to grips’ with a situation. Enduring is the blocking of the emotional response; emotions are suppressed, squelched, sealed off. Enduring is a strategy that enables the person ‘to go through the motions,’ doing what must be done...[It] permits the person to continue day-to-day functioning, but the internalizing of emotions does not bring relief. The person *must* experience an emotional release *if* healing (i.e., healing that is not of the physical body) is to occur. (Morse, 2001, p. 50).

Participants’ descriptions for the theme of enduring reinforced the distinct yet entwined and interconnected nature of enduring and suffering. This cycle of suffering with two distinct states of enduring and suffering has been established by other researchers (Duggleby, 2000; Georges, 2002; Morse and Carter, 1995, 1996; Sundin et al., 2000). Morse’s primary leadership in this field has propelled consideration of enduring as distinct and unique from suffering through her *Praxis Theory of Suffering*; enduring and suffering are “diametrically opposite; each demands that the person be treated in a distinctly different way.” (Morse, 2001, p. 50). The level of enduring for each participant was impacted by the intensity, duration, delays in diagnosis or treatment of conditions, and/or multiple suffering events. Morse (2001) acknowledged that both enduring and emotional suffering or releasing vary in intensity, other distractions present, and the overall context (p. 56), but at some point an emotional release must occur for healing to occur.

The enduring mode and the state of suffering appeared as unique states, yet maintained a fluid boundary, melding or blending together into one state, making it a challenge to assess or recognize. Participants offered clear and dominant expressions of this enduring state, yet they also offered expressions of suffering, blending the two states throughout their accounts of their suffering experiences. This non-linear cyclical nature of enduring and suffering was illustrated in Morse's *Praxis Theory of Suffering* and her *Model of Suffering* (2001, p. 54). Morse and Carter (1996) offered a description of the dynamic nature of the relationship between suffering and enduring, "While some persons may become stuck in enduring or in suffering, most move involuntarily, rapidly, suddenly, and unexpectedly between the two states" (p. 56). The state of enduring, emotional suppression, focused on goals of awareness and recognition for suffering, while the state of suffering or emotional releasing, supported the attainment of acceptance. Morse observed that persons who endured did not move into emotional suffering until they were ready to accept their loss. This transition was tentative, dependent on reserves of energy and a sense of control to overcome the fear of disintegration (Morse & Carter, 1996, p. 53). A key part of Morse's model of suffering was the acknowledgement of suffering, forming the bridge or transition, between both states, to move a person from emotional suppression (enduring) to emotional releasing (suffering).

Morse and Carter (1996) also established three types of enduring: (a) *enduring to survive*, a physiological endurance in which the client just tries to live through the experience; (b) *enduring to live*, a psychological endurance, in which the client seeks to protect themselves from the pain; and (c) *enduring to die*, both physiological and

psychological, in which persons seek to have a peaceful death. These types of enduring were relevant for this study. '*Enduring to survive*' was confirmed for participants during their toughest moments of crisis in suffering, and was primarily physiological; while '*enduring to live*' was relevant for emotional and spiritual experiences of suffering. '*Enduring to die*' didn't impact any of the participants directly, but one participant offered an account of his indirect experience through his mother's death experience with '*enduring to die*.' He observed how she had shut down and relinquished control over decisions to pursue further treatment, shrugged off her caregiving role for his father, and essentially waited for death.

A longing for help became apparent as persons shared stories of enduring. Persons expressed a desire for help, but appeared to be hesitant or even incapable of asking for help. Lohne's (2005) longitudinal study with ten persons who suffered spinal cord injuries revealed the significance of hope and discussed two themes expressed by these persons as a "vicious circle" and "longing," revealing the long road of recovery and a search for renewed meaning. This longing for help has not been examined in extensive studies. Persons lacked energy to interact and often refused help from others due to their limited energy reserves. A narrow window of opportunity or openness to external intervention limited others' ability to penetrate this seclusion. Morse and Carter (1996) discussed the extensive reserves of energy that enduring requires, supporting the endurer's choices to minimize interaction that could threaten their limited energy sources. Raholm, Lindholm, and Eriksson (2002) show how a spiritual connection can help to draw a person from this isolation, "every human being needs time and space to suffer, a balance between loneliness and communion" (p. 8). They saw this acceptance of a

person's vulnerable position as spiritual care. Lindholm et al. (2005) linked longing to wishing for hope. They indicated that hope can be awakened by attentive listening and by asking patients to describe their desires.

The turning point or transition between enduring and moving on to suffering, recovery and healing, involved intentional decisions and required action. This was a vulnerable and tender stage, but key for survival and living. Rehnfeldt and Eriksson (2004) distinguished this turning point between "bearable and unbearable suffering," marked by an acute need to express oneself, to gain communion with others. A recall of significant events and actions supported this important junction between enduring and what followed. Rehnfeldt and Eriksson hinted at maximizing any opportunity to intervene with a person in enduring as they inferred that the patient could get trapped in sustainable suffering if he or she was not cared for by the caregiver to help him to reach the turning point. Several persons expressed how a sense of emotional detachment lingered in their lives; limiting or prolonging their ability to heal. Could this extended state of enduring, reaching for years beyond the initial suffering event, be prevented? Further study for this complication of prolonged detachment and potential interventions is recommended.

Hope was expressed as a crucial need during enduring and in suffering, but was often lacking for participants. Persons expressed a passive pursuance of hope. A reliance on external sources of hope surfaced such as hope gained through the interventions and encouragement from others. Duggleby's grounded theory analysis (2000) offered support for the significance of nurturing hope for persons who suffer, but more study on hope's relationship to enduring is needed. Perry (2009) indicated that the "cruellest words that

are ever uttered by a health professional are “There is nothing more that we can do for you”” (p. 19). Participants agreed that these words shattered their sense of hope and appeared to trigger a deeper state of enduring, one leading to despair. Lindholm et al. (2005) reflected that “hopelessness is related to doubt, apprehension, and fear; hope gives inner peace, a sense of confidence, and a feeling of freedom” (p. 36). A positive approach to instill a sense of courage was offered by Tyler-Ball (2007), to “answer the call of entering the empty spaces in the human heart caused by suffering, courage and commitment are truly required” (p. 82).

Beyond Suffering – Recovery and Healing

The next study aim challenged participants to explore their perceptions of healing and altered self-perceptions which related to the theme, beyond suffering, recovery and healing. Responses were dependent on each participant’s current physical condition and stage of healing at the time of their interview. All participants identified with altered self-perceptions. One person was clearly beyond their major suffering events while most persons were in the midst of healing. Only one person could not relate to any level of healing due to an undiagnosed condition. An essence summary description, based on participants’ recovery and healing perceptions included:

A “new normal’ captured the essence of healing and recovery beyond life-impacting suffering. This ‘new normal’ was occasionally better, but for most persons required and demanded more effort to adapt, to change, and accept the losses due to one’s suffering events. Goals and benchmarks helped to motivate and encourage progress, but changes were slow and subtle, difficult to identify moment by moment or even from a day to day perspective. This gradual process of healing involved delicate issues. One was a sense of fragility, teetering on the edge in a vulnerable state, while another was waiting and wondering about the pace of recovery. Other concerns involved the issues related to learning to live with or treat the physical, emotional, or spiritual pain that lingered after others thought you’d recovered. Taking charge of this ‘new normal’ helped others get to

the next place in life, while support from others was cherished even if at times rarely offered. Getting back to work was a goal for many, but timing and energy were crucial ingredients for success in resuming life and patching together a 'new normal.'

Some persons realized how far they had come following their suffering and were very grateful for having endured the tests and experiences along their journey while others were eagerly anticipating and hopeful for a taste of freedom due to healing.

Most persons offered some insights about the theme related to altered self-perspectives as a result of their suffering experiences. These alterations in self-perspectives based on participants' suffering experiences, were elaborated in this essence summation:

Expressions of joy and thanks; suffering turned to joy for surviving it and celebrating its grip on one's life. Suffering was a teacher and helped one grow personally with new traits or characteristics that emerged; traits such as the ability to accept help from others rather than being the giver of help. Some had to 'watch and be, rather than do' and learned to accept it and even thrived. Faith deepened, as one recalled there was no choice but to turn to God. Some persons accepted what happened and moved on in life, but one person wondered what was learned except for a realization that suffering taught a 'brutal lesson.' The purpose of suffering and its personal meaning meant self-renewal, a desire to refocus on what really mattered, waiting for some 'ah ha' moment. Surviving a close brush with mortality changed a 'death sentence to a life sentence.' Relationships deepened; some saw and felt how others suffered and reached out to them with a desire to reciprocate the care they had received in their hour of need. Having gone through it, they wanted to help another through their 'knothole, it's all about knotholes.'

A freedom was felt and expressed as those who suffered could see their gradual release from the bondage of suffering with a future awaiting them with hope and growth.

This state of a 'new normal' for healing was also holistic in nature. Smith (2001) defined healing as a change of one's perception about circumstances or a problem and reflected that "it is possible to be cured yet not healed, and to experience healing without being cured" (p.22). Wayman and Gados noted how a level of personal surrender was

required to be able to adjust to an altered life following suffering and to accept what could not be changed (2005). The process of surrender to necessary life adaptations often led to a state of acceptance. Acceptance for the 'new normals' offered freedom from the bondage that suffering had imposed on their lives. However, for some participants the ability to fully accept life-impacting changes and the resulting complete healing was limited by barriers. Physical healing was limited by complications, and spiritual healing was blocked by a disconnected faith in one's relationship with God or their supreme being. Another barrier, a long-term detachment that lingered from the enduring state, rendered part of the sufferer's experience as 'out of bounds,' or off limits. Their specific emotional pain was too intense or threatening to face. It had been walled off too long, and was for the moment unreachable. Further examination of the impact of this long-term detachment from the enduring state is required. Morse and Carter expressed sufferers' readiness for healing, "When sufferers are ready, have 'suffered enough,' reached acceptance, and integrated the past into their lives, only then can they move on" (1996, p. 58).

Altered self-perceptions due to life-impacting suffering were common to all study participants. Wayman and Gados (2005) offered one outcome for suffering survivors as "treasures and gifts." Treasures that were noted in this study included the recognition of the power of unconditional love and the renewed relationships with family and friends, congruent with the "reformulated self" (Morse & Carter, 1995, 1996). This renewed vibrancy in interpersonal relationships often extended to others beyond themselves. A deeper awareness and regard for others who suffered was expressed as "helping others suffer through."

Role of Family and Professional Caregivers

The final aim of the study addressed the role of professional caregivers' assessment of enduring and suffering and its impact on the sufferer and their families. Insights related to assessments of unique aspects of suffering and enduring were revealed. Persons also expressed profound feedback related to their perceptions of effective and ineffective supportive care from families and professional caregivers. An essence description for the themes of family care and support, as well as family issues emanating from the provision of support follows:

Suffering was lonely and isolating. Enduring was even more lonely when the person was lacking the strength to respond or interact, and others around them didn't realize what was happening. Others could and did make a difference in many ways, through their support for the sufferer. But it took much effort, persistence, and understanding. Family and friends gave their presence, their unconditional love, their support with decisions, even when they were also suffering in their own way. Family helped in many ways, by letting the sufferer suffer, not forcing them to hide their suffering or deny it, but with permission and encouragement to stumble through the pain. On the other hand, tensions mounted in families as they dealt with the pressures and burdens and the pervasive sense of powerlessness. Family and friends reached out and helped with prayers, words backed by action, and with time and space for healing. But children were often shielded from the negative forces of suffering, but were they spared from this?

Family support was absolutely essential, yet often resulted in disrupted family dynamics and its sense of equilibrium known by family members.

The role of family. The powerful and positive role of families was revealed through stories offered by those who suffered. A high level of interview coverage focused on how helpful families had been with very low emphasis on ineffective support by family members. This may have been influenced by an above-average level of functional families involved in this study. Families were best prepared to respond to their loved ones' needs in meaningful and caring ways. Personal gestures of presence and helpful

caring actions meant most to their loved ones who suffered. The gift of time and space to heal was cherished from spouses and other family members. Several of the middle-aged participants related how their mothers had played a significant role in their care during their suffering events. Further exploration and study of middle-aged persons' continued reliance on parents, particularly mothers, may be warranted. Children were also intentionally shielded from the negative effects of suffering. Long-term implications of this also need further examination.

The demands of decision-making and a sense of powerlessness were noted as significant family issues. Decisions necessitated by suffering experiences and its interventions were shared with family members but often escalated marital and family tensions. These sources of conflict united most families and married couples and potentiated the strength and growth of their relationships as they were forced to work through conflicts in order to manage the suffering and its impact on them. Yet the potential for unresolved conflicts based on the impact of suffering in family's lives was present, its power to wreak havoc on family relationships was always present. The threat to a family's autonomy and family members' dignity imposed by suffering rippled through families. Family members and partners experienced suffering in distinct often uniquely intersecting ways from their suffering family members as noted by the theme of parallel suffering. Monin and Schulz (2009) offered an observation from their study with gerontologic populations suggesting that "theory and empirical evidence suggest that individuals are vigilant to a relationship partners' physical and emotional distress and often experience similar emotions and/or complementary emotions" (p. 681). Spouses were compelled to step in and take over areas and decisions of their partner's lives while

children were often shielded from suffering's fury. This interrelated nature of suffering was felt by all families. Monin and Schulz offer extensive evidence for the interpersonal effects of suffering within families.

Role of professional caregivers. Finally, the study participants revealed desirable care and support from their professional caregivers, summarized in the following essence narrative:

Sufferers yearned to be understood and known by their caregivers; supported by actions more critical than words. Abandonment by anyone was a threat. Caregivers were coveted for their presence, their follow through with their promises, dependability, sensitivity, and respect. Hope was huge and sufferers struggled mightily to hope. Sufferers looked to their caregivers to remain steadfast as they longed for these professionals to: Listen intently, to care, to see and recognize, and to feel their suffering. Be professional, avoid scolding them, putting them off, or hiding from them in your tasks. Look at those who suffer, really look at them to see and hear what is going on, what is really going on with them and their family. Disguise your busyness. Give them time and space to heal. Inform them, but heed the timing so it will not overwhelm or confuse them. If they as sufferers can't respond, realize that they truly can not respond and let them know it does not matter for now. You, the caregiver, will be present and wait for them.

Acknowledging ineffective supportive care was equally as valuable as learning what was significant for effective care for those who suffer.

Participants had less to offer about positive caregiving relationships compared to support they had received from their family members. Some of the recollections of positive support were tied to professionals who were able to instill hope, those who used humor to connect, and those who were more pro-active in their care. Continuity with the same caregivers assigned to them and those who displayed a desire to "know me" were valued. Professionals who checked back to evaluate if their care had been effective and followed through with promises, whose actions were more critical than their words, were

appreciated. Professionals' calm and deliberate demeanors were noticed, and those who offered prayers with sufferers and their families were appreciated.

The level of ineffective and non-supportive professional care was most prominent in discussions related to the theme of care and support. A consistent message conveyed by participants related to a lack of holistic focus in their care, despite the evidence for the holistic natures of enduring, suffering, and healing states. Participants shared a consistent neglect of their emotional and spiritual needs which were rarely addressed by their caregivers. The sub-themes offered for this need for effective care and support point to three significant areas to address in professional caregiving: (a) positive changes in a higher level of professionalism, (b) a stronger acknowledgement of individual, person-centered needs, and (c) careful and well-timed sources of information to guide the sufferer through their suffering experience.

Professionalism, focused on the provision of attentive presence, without apathy, avoidance, long delays, and discrimination was desirable. Persons desired open access to their health professionals at their time of need and not blocked by receptionists who limited their access and ability to connect with their health providers. The professionals' desensitization to their suffering was obvious to those who suffered, the apathy and avoidance became a barrier to their professionals' acknowledgement of their unique needs related to suffering. Persons wanted professionals to acknowledge their needs with person-centered care; to listen, to offer their undivided attention without projecting 'busyness' and a focus on tasks; and attention to their holistic needs, including emotional and spiritual needs was important. Carnavale (2009) discussed the need for "empathic attunement...an attempt to grasp a sense of the felt emotion of the other." (p. 181). He

also called this “attentive engagement,” or an attempt to sense the meanings one associates with the emotion of suffering (p. 181). Participants yearned for professionals to look at the “big picture” and not just urgent needs for that particular day or time.

Accurate and reliable information presented power over enduring and suffering. Due to the limitations in communication that sufferers presented during the state of enduring, access to information was limited. Enduring persons may not even be able to hear or process key information to gain insights about their condition. A reliance on family members or significant others to filter information during the enduring phase was shared. This reinforced the need for ‘just in time’ education about current and future interventions, treatments, and projected outcomes. Johanssen, Roxberg, and Fridlund, (2008) offered insights about timing of information which was consoling to their patients:

Precise and correct information should be provided in dialogue with the patient was described as an important element of the act of consolation. It was also important to choose the right time for presenting the information. The place where the information was given, as well as how it was given and followed up was of great importance (p. 20).

Anticipatory updates along with education about cues for anticipated pain and recovery changes were requested. Due to the long-term nature of suffering and its interventions, a primary care coordinator was also requested as a primary advocate, one who could help to minimize all of the conflicting information so typically offered by so many health professionals that were involved in one’s care.

Professional caregivers needed to acknowledge that suffering and enduring are work (Duggleby, 2000). Recognition that suffering is a drama (Raholm et al., 2002; Perry, 2009) and responses need to be sufferer-led (Morse, 2000) lends a supportive foundation for all professional interactions and interventions. A holistic focus is crucial to

match the holistic nature of suffering, enduring and healing. Assessment and astute recognition (Morse, 2000; Hallowell, 2006) of the subtle cues of both suffering and enduring will help one to develop “empathic attunement” (Carnavale, 2009, p. 181). Morse (2000) offered comforting strategies for enduring that support the person to endure and maintain emotional containment by simply offering presence, or words of encouragement that a person is “bearing up” or coping well. Conservation of an enduring person’s energy and support for patient’s focus and using one’s voice with comforting talk is helpful (Morse & Carter, 1996). An important difference to note between enduring and suffering involves the cue for approach. Enduring persons send the message “leave me alone,” while persons who suffer and want to express emotions send the message to comfort, draw near, and touch (Morse, 2000). Sympathetic or empathic statements or physical closeness will increase an enduring persons’ distress and should be avoided. In contrast, comforting strategies to support the release of emotions in suffering are different. Empathy, sympathy, condolences, touching, hugging, and physical closeness are appropriate to help absorb a person’s distress (Morse, 2000). Morse’s work with suffering has confirmed how important, yet difficult this phase of suffering is for persons. It is hard work, very hard and at times, unpleasant work, and it should not be confused with depression or muted with medications. Anticipation of the needs of enduring and suffering patient and their family will help to minimize the effort expended in the work of suffering and enduring.

The importance of addressing the unique needs for the person who endures suffering was confirmed by this study. This hinges on the recognition that the enduring state is distinct from suffering. Professionals need to be educated regarding the unique

characteristics, needs and work of persons who endures. Careful assessment for a person who presents holistic aspects of shutting down will indicate a person's individual needs during this phase. This assessment is critical because the enduring person's ability to communicate or ask for help is limited. Persons may be enduring their greatest hour of need and not be able to share this and may even possibly refuse help that is offered because of the energy that will be expended for any response. The enduring state is characterized by drawing inward, leaning on one's self-dependence, and self-reliance. Hope is very hard to grasp without external hope sources and sustaining hope by oneself may pose a constant battle. Persons shared how helpful external offers of hope were for them, but it was important to offer this hope repeatedly, particularly during this enduring phase.

Gaining a sensitivity to learn and assess when a person is ready to transition from enduring to the suffering state is essential. This is a vulnerable and delicate transition, and if done too soon, can erase the ability of the sufferer to emerge, even briefly, from the state of enduring. Professionals need training and a heightened awareness for finding 'windows of opportunity' when enduring persons have enough energy, strength, and a desire to interact and break free from the enduring mode. Sensitivity for effectively timed interventions is another important consideration for the professional's interactions and teaching during enduring. One hazard is pushing too hard and forcing a person out of the enduring mode when they are not ready. Assessing for 'readiness to suffer' is important before asking an enduring person to express the feelings they are not yet ready to share and enter the suffering and pain they can not yet face. Communication styles for persons who endure do not follow typical interventions, but need to be sufferer-led rather than

offered according to the professional caregiver's timing and agenda. A fear of rejection or lack of attentiveness to a person's suffering dilemma is countered with the "unwavering commitment" by professionals (Cutcliffe, 2006a; Johannssen et al., 2008). This threshold, or turning point, hinges on the person's ability to make decisions and intentionally act to press ahead and to escape the enduring mode. Acceptance of the sufferer's pace and supporting the sufferer to lead is crucial.

Impact of suffering on nurses. Evidence from this study did not focus directly on the impact of suffering on nurses. However, two areas of concern were expressed by study participants. One area included how nurses, or health professionals, compounded the patient's suffering through attitudes of apathy and insensitivity for persons' nature and level of suffering. Steeves et al. (1990) depicted how the realization by nurses that they contribute to patients' suffering has caused some of them to leave the profession. The other concern related to nurses' willingness and/or their ability to commit to the relationship with the sufferer with the level of commitment and courage required for effective assessment and intervention. For some nurses this limitation or reluctance was impacted by their orientation to tasks more than interaction, their inadequate communication skills, and their fear of over-involvement. Maeve (1998) addressed similar themes in a phenomenological study with nine nurses focused on how nurses live with the suffering and the dying. Maeve's study revealed three themes for coping: (a) tempering involvement, such as setting limits and boundaries, coming to love or not love a patient; (b) doing the right/the good thing, involving competency; commitment, and courage; and (c) cleaning up, literally to soothe ones' sense of loss and grief with

dying patients and a need to self-review in difficult patient encounters. These themes of tempering involvement and doing the right/the good thing validated these findings.

Implications and Recommendations

Recommendations and Implications for nursing practice

Based on the premise of relevant and impartial study findings, the participants' lived experiences of suffering and their views on effective and ineffective supportive care can guide health care professionals, such as nurses, to enhance acknowledgement of some 'best practices' for those who suffer. This study raised awareness for how nurses can improve the recognition and assessment of the impact of suffering on patients and their families as well as how suffering can steal a "normal life and livelihood." Stronger support for holistic assessments and supportive care for those who experience life-impacting enduring and suffering is vital so that nurses better understand and implement client and family-centered nursing care that truly addresses their individual holistic needs.

Based on the findings that showed that emotional concerns were more prevalent than physical issues; a heightened awareness for the holistic needs of all suffering persons is warranted. Persons who suffered also expressed spiritual needs during interviews, but felt that hospital or clinic environments impaired their freedom and comfort to talk about their spiritual concerns and hindered spiritual practices such as prayer. Nurses should promote depression screening, assessment for traumatic emotional and physical experiences, assessment of heightened sensitivity to sensory impairments or experiences, as well as the assessment of spiritual needs and desired spiritual practices. Anticipatory education to address all potential issues, but particularly emotional and spiritual issues during short-term as well as long-term recovery periods, are critical to

fully support persons and their families who suffer. Offering educational sessions to advance effective assessment and intervention skills for those who suffer, with potential scripting or guided interview questions for patient intakes and rounds may facilitate a more focused assessment related to suffering. Facilitation of spiritual support and practices, such as prayer, should be offered, as well as considerations for privacy. During the passive states of enduring and suffering, nurses may ask permission to pray for the person, or make arrangements for others to pray or implement other religious practices for persons who can not perform these valued practices independently. Inclusion of family and any other significant others' support and interactions should be offered and encouraged, to maximize those who best know and understand the suffering person.

Counseling and pastoral care services are typically available during in-patient care, but out-patient referrals should be considered on a more frequent basis with in-depth consultations encouraged for persons with major life-changing events. Anticipatory discharge planning will address the expressed needs for follow-up community support groups and education for family members who commonly offer primary support in these areas. Helping loved ones learn to identify the devastating impact on their loved ones and equipping them with resources to help them with these needs prior to discharge will promote a smoother transition to home when persons will need to make adjustments to manage their care.

Health professionals may have limited knowledge about the impact of experiences of enduring for patients who experience intense, multiple or lengthy suffering events. Education is needed to better promote an understanding of the impact of the process of 'shutting down' during the enduring process of suffering. Implications for care related to

enduring should address the sufferer's "moment-by-moment" present orientation with a limited ability to focus; because lengthy explanations or long-term schedules with a focus on the future would not be appropriate. Helping the enduring person to complete one action at a time, such as breathing exercises or re-positioning, with time to rest before another action may help them to re-establish a stronger sense of control and motivation for recovery. Expectations for decision-making may need to be postponed or deferred to family members. Communication methods may need to be adjusted to discuss primary concerns from the patient's perspective rather than the caregiver's perspective. Asking questions that help the client make choices about how they want to expend what little energy they have may help the person feel understood and encouraged to re-engage in life. Being aware that it may be difficult or impossible for the enduring person to speak and request help, may help the professional be more pro-active as they support the person who endures in their greatest hour of need.

Effective support for sufferers and their families focuses on attentive care that fosters trust and accountability. Active listening and conveying a calm and deliberate focus is very important, because there may only be a limited window of opportunity for interaction. Giving persons time and space to heal may be difficult to do with nursing routines, but should be offered as much as possible. Supportive hope-building attitudes and actions with follow-through are critical. Maintaining professionalism, free of hints of apathy and task focus is important to enhance relationship-building with suffering individuals. Humor is desirable but not at the expense of those who suffer. A realization and awareness for the needs of spouses or partners, as well as children, will also support

the person who suffers. Family tensions may surface, and should be anticipated. Privacy and space may be helpful as families work through their delicate issues in a difficult time.

The study has also explored person's perceptions of healing and alterations in self-perceptions due to life-impacting suffering. During this phase of suffering, nurses and all health professionals need to provide continued support. Education is imperative related to issues of self-care, motivation, self-assessment of pain cues, and expected timing issues in recovery such as wound healing and depression. Routine information for signs and symptoms of the inflammatory response has become common practice, but what about the signs and symptoms of enduring and emotional suffering cycles? Additional support is often needed in areas of gauging persons' readiness to resume work. Persons need to know that there are many choices that they can make with the support of their healthcare professionals to minimize feelings of vulnerability as persons adjust to life with a 'new normal.' Career counseling may be valid for those persons who will not be able to return to their former employment, but who want to make plans rather than delaying this until later in their recovery.

Support for person's altered self-perspectives may be warranted, particularly if persons have experienced a major shift or find themselves experiencing a sense of disequilibrium in their lives. Change, even positive change, can add stress to persons who have already been bombarded with stress and discord in their lives. Disruptions in routines, family dynamics, and roles should be addressed and anticipated. Helping lend support for the "ah ah" moments, when persons may see the fruits of their suffering experiences, such as renewed relationships, personal growth, or being able to reciprocate help to another person in need all can boost a person's self-esteem or sense of life

fulfillment. Supporting a search for what was gained may help to support the grief over losses experienced.

Though the study did not address professional burdens related to the impact of suffering and its toll on nurses both personally and professionally, demands for advancing the expectations for deepening nurses' assessment and interventions for the suffering person could raise the risk for increased professional burnout. However, more involvement and a deeper level of engagement for nurses who experienced a more personal reciprocal caring exchange with patients might actually reduce the risk for nurse or caregiver burnout. The professional burdens could be balanced with a heightened sense of personal and professional rewards gained through this interpersonal response.

Recommendations and Implications for Nurse Educators

For nurse educators, this study's findings revealed the need to facilitate students' understanding of the complexity and scope of suffering for their clients in healthcare situations and to learn effective and meaningful 'best practice' interventions that will help students to address the suffering needs of their clients. Carnavale (2009) supported how "significant shifts in the educational preparation of health care professionals are needed to enable them to recognize the complexity of patients' emotional and suffering experiences" (p. 182). Students need to be given realistic and positive experiences with suffering persons during their educational clinical experiences, with active guidance and faculty support to offer assistance for tailoring and individualizing their assessments and interventions with each suffering client. One key content area to add to the curriculum tied to suffering would include the distinct phases of enduring and suffering, and the inclusion of its specific symptomology and interventions for each phase.

Clinical conferences should focus on discussions of the holistic areas of suffering, the phases of enduring and suffering, and effective care and support. Supporting persons to seek healing and arrange for comprehensive post-discharge care planning should also be included in the clinical curriculums for nursing students.

One tool that has been effectively utilized for several years by the researcher and other faculty members is a suffering interview, which gives students' scripted questions to guide their intake and ongoing assessment (see Appendix E). The goal of this assessment tool is to help students gain a realistic perspective for the depth of issues they will experience in their future careers with suffering patients as well as potentially advance their interviewing and communication skills. This suffering interview asks students to self-select and identify a person known to be experiencing life-impacting suffering. The holistic interview helps students to ask tougher and deeper questions. This often proves to be a challenge for the student, but helps them to better utilize an open-ended approach to this focused assessment. These interviews are purposefully divided into several interview settings to give the suffering person time and space to share their story in approximately 30 to 45 minutes. Personal reflection questions are included to help the student process the impact of this interview for themselves, with personal and professionally oriented reflection. A group debriefing class session can follow the completion of this exercise to give students further debriefing opportunities and to enhance peer and faculty support. This group debriefing could serve as a model for methods to conduct future support sessions with coworkers in clinical practice settings.

Limitations

Limitations related to design and analysis methodology that could lead to mistaken findings could stem from issues of rigor, trustworthiness, and the transferability of findings. To enhance credibility, member checks were completed for all transcriptions of interviews with all participants. The researcher and a peer reviewer also validated transcripts with audio-taped interviews. Triangulation was achieved through multiple data sources including eight interviews and two journals. Investigator triangulation occurred through consultations with the dissertation advisors and peer reviewers. Confirmability of findings was enhanced with maintenance of an audit trail for the data analysis process. Multiple peer debriefing sessions were held throughout the process of data analysis to maximize the dependability of the findings. Saturation of data for each theme along with rich, thick descriptions and quotations of participants' stories of suffering were shared to augment the transferability of the findings.

A small sample of eight fairly homogenous participants could limit the findings, but saturation of data was achieved for themes and this sample size is characteristic for phenomenologic qualitative designs. One challenge was experienced with the recruitment of appropriate participants due to a purposive sampling method. One of the unanticipated issues included having to postpone interviews for several participants who were either too physically ill or emotionally distressed, or unable to give voice to their lived experiences when they were experiencing the 'shutting down' phase of enduring. Participants were given encouragement to wait until they were ready to speak, and were always given the option to opt out of this voluntary role. No participants did opt out, but one participant delayed their interview for several months following the researcher's initial contact.

The risk of stimulating more emotional distress for participants resulting in a distortion of one's view of suffering may have occurred during interviews when suffering experiences were relived. Participants were encouraged to contact the researcher for continued support or a potential referral for counseling services, but none requested these services. The researcher did establish emotional connections with participants due to the intimate and moving nature of their suffering stories, but no known issues of dependency arose. Finally, the researcher was impacted by the highly charged emotional content of the interviews and throughout data analysis with the repetitive reading of highly emotional-charged content of interviews, which at times delayed progress with data analysis. A need for self-care and external support from family and friends was vital to sustain a balanced self-perspective throughout this process of interviewing and analysis.

Delimitations

Delimitations that may limit relevancy of this study to other populations or individuals are cultural factors, age, gender, unique aspects of suffering, natural settings, and availability of social support. Cultural practices and beliefs, as well as age and gender variances may influence how individuals view and experience suffering. Deviant case sampling, which could involve those participants who have experienced very little or very much suffering, may not truly represent the typical suffering experience representative of the majority of the population. The recruitment of participants for this study who had maximum variation for any type of suffering should have captured a wide range of diverse suffering viewpoints, and intensity sampling should have fostered the inclusion of persons who experienced a lot, but not extreme levels of suffering (Polit & Beck, 2008, pp. 355-356). Even with careful sampling techniques, length and type of

suffering experiences as well as number of suffering events were varied. Variances in natural settings for participants' suffering also altered levels of support and financial means for seeking ways to address needs and any required health care or mental health services to facilitate coping with suffering. Differences in levels of family support or support from significant others was a variable that could have presented difficulties for participants' descriptions of their suffering story.

Future Research

Based on the findings and evidence of this study, many topics for future research have been introduced. One critical area for future study revolves around the need to establish further evidence for therapeutic communication styles tailored to the needs of suffering and enduring, which could potentially counter current views of therapeutic communication styles in nursing practice (Morse & Carter, 1996). Further examination of 'sufferer-led' best practices for assessment and interventions should be completed to better direct nursing response. Based on the fairly homogenous demographics of the sample for this study, further consideration for the influence of persons' suffering variables such as age, gender, and culture should be completed. Cultural components of suffering have not been emphasized in this study, nor has the study of sufferers who may not have any family support systems, or those persons who have a dysfunctional family that would limit effective family caregiver support.

Based on the themes of parallel suffering and family tensions when suffering stuns the equilibrium of a family's dynamics, examination of role reversals following suffering's assault within families could also offer insights to guide family members, particularly those who serve as primary family caregivers. An additional family impact

for further study might include how children, who may be shielded from the onslaught of suffering, recover from the life-altering impact of suffering's cruel effect.

Closer examination of specific components of findings related to the phase of enduring also demand further scrutiny. Questions posed about enduring include how the phase of enduring may limit support from others, and why some persons appear to endure longer than others. Development and research of effective assessment tools for both suffering and enduring would help to guide recognition and interventions for those who suffer to reduce the damage done when suffering is hidden from professionals and goes unaddressed.

Further exploration for other holistic dimensions of suffering, such as the role of sensory influences that mimic traumatic experiences, disclosed by several study participants, could also benefit from additional study. This also prompts more questions related to issues of effective timing and the outcomes of any confrontational interventions for emotional suffering. How does encouragement for direct interventions, such as encouragement for sufferers to give voice to their suffering for unacknowledged conflicts and the 'sensory memories' linked to their emotional turmoil, influence one's movement from enduring to recovery from suffering? Would more direct intervention promote persons to reach the turning point between enduring and suffering sooner, or would it interfere with the enduring person's ability to set their pace for recovery? Further study is indeed justified to carefully guard the vulnerability of persons who suffer.

Summary

In this chapter, focus on the interpretation of findings and their correlation to supportive literature has been presented. Implications for nursing practice and education

have been offered as well as challenges for future research. Limitations that may detract from the findings have been addressed. Based on the phenomenological qualitative approach for the exploration of the lived experience of suffering, altered perspectives and understandings have been offered to hopefully further the study of this challenging phenomenon.

Much is yet to be known and understood about suffering, despite the long-term focus on this phenomenon. The lived experience of suffering pervades all aspects of patient care, and should be a central focus and foundation for nursing care and education to prepare nurses and all health professionals. The alleviation of suffering needs to be sustained as the heart of nursing. This will take time and attention in an already packed schedule of care, but it should be woven into the threads of all patient care. After all, most nurses enter and pursue the nursing profession due to their calling and desire to influence others' lives in a meaningful way. But the urgent, more concrete and measurable, and often more prescriptive patient care priorities crowd out nurses' intentions to make a holistic difference in the lives of their patients. With a desire to address and understand the dominance of suffering for many patients, nurses can be better prepared and less fearful to care for those who suffer. Suffering persons' lives will still be imprinted by their suffering, but they will be given support, understanding, knowing, and a better opportunity for the complete healing and recovery that they long for and deserve.

References

- Achterberg, J., Dossey, B., & Kolkmeier, L. (1994). *Rituals of healing*. New York: Bantam Books.
- Adam, R., Tilley, S., & Pollock, L. (2003). Person first: What people with enduring mental disorders value about community psychiatric nurses and CPN services. *Journal of Psychiatric and Mental Health Nursing, 10*(2), 203-212.
- Arman, M., & Rehnsfeldt, A. (2006). The presence of love in ethical caring. *Nursing Forum, 41*(1), 4-12.
- Arman, M., & Rehnsfeldt, A. (2007). The 'little extra' that alleviates suffering. *Nursing Ethics 14*(3), 372-386.
- Arman, M., Rehnsfeldt, A., Lindholm, L., & Hamrin, E. (2002). The face of suffering among women with breast cancer - Being in a field of forces. *Cancer Nursing, 25*(2), 96-103.
- Arman, M., Rehnsfeldt, A., Lindholm, L., Hamrin, E., & Eriksson, K. (2004). Suffering related to health care: A study of breast cancer patients' experiences. *International Journal of Nursing Practice, 10*, 248-256.
- Attree, M. (2001). Patients' and relatives' experiences and perspectives of 'good' and 'not so good' quality of care. *Journal of Advanced Nursing, 33*(4), 456-466.
- Beecher, H.K. (1957). The measurement of pain. *Pharmacologic Review, 9*, 59-209.
- Black, H. K. (2006). The sacred self: Suffering narratives in old age. *Omega: Journal of Death & Dying, 53*(2), 69-85.
- Black, H., & Rubenstein, R. (2004). Themes of suffering in late life. *Journal of Gerontology, 59*(1), 817-824.

- Burton, L. A. (1992). *Religion and the family: When God helps*. New York: Haworth Pastoral Press.
- Carnavale, F. A. (2009). A conceptual and moral analysis of suffering. *Nursing Ethics* 16(2), 173-183.
- Cassell, E. J. (1991). Recognizing suffering. *Hasting Center Report* 21(3), 24-31.
- Cassell, E. J. (1994). *Pain and suffering*. *Encyclopedia of Bioethics*, 4, (1897-1905). New York: Macmillan Library Reference USA.
- Cassell, E. J. (1999). Diagnosing suffering: A perspective. *Annals of Internal Medicine*, 131(7), 531-534.
- Copp, L. A. (1974). The spectrum of suffering. *American Journal of Nursing*, 74, 491-495.
- Cutcliffe, J. R. (2006a). The principles and processes of inspiring hope in bereavement counseling: A modified grounded theory study - Part one. *Journal of Psychiatric and Mental Health Nursing*, 13(4), 598-603.
- Cutcliffe, J. R. (2006b). The principles and processes of inspiring hope in bereavement counseling: A modified grounded theory study - Part two. *Journal of Psychiatric and Mental Health Nursing*, 13(5), 604-610.
- Duggleby, W. (2000). Enduring suffering: A grounded theory analysis of the pain experience of elderly hospice patients with cancer. *Oncology Nursing Forum*, 27(5), 825-831.
- Egnew, T. R. (2005). The meaning of healing: Transcending suffering. *Annals of Family Medicine*, 3(3), 255-262.

- Eifred, S. (2003). Bearing witness to suffering: The lived experience of nursing students. *Journal of Nursing Education*, 42(2), 59-67.
- Eriksson, K. (1981). The patient care process-An approach to curriculum construction within nursing education. The development of a model for the patient care process and an approach for curriculum development based on the process of patient care. Unpublished doctoral dissertation. Helsinki University, Pedagogiska Institutionen, Helsinki, Finland.
- Eriksson, K. (1990). *Pro Caritate. En lagesbestämning av caritativ vard* [Caritative caring: A positional analysis]. Vaasa, Finland: Abo Akademi University Department of Caring Science.
- Eriksson, K. (1995). *Mot en caritativ vardetik* [Toward a caritative caring ethic (Ed.)]. Vaasa, Finland: Abo Akademi University Department of Caring Science.
- Eriksson, K. (1997). Understanding the world of the patient, the suffering human being: The new clinical paradigm from nursing to caring. *Advanced Practice Nursing Quarterly*, 3(1), 8-11.
- Eriksson, K. (2002). Caring science in a new key. *Nursing Science Quarterly*, 15(1), 61-65.
- Eriksson, K. (2003). Ethos. In K. Eriksson & U.A. Lindstrom (Eds.). *Gryning II- Klinisk varvetenskap* [Toward a caritative caring ethic]. Vaasa, Finland: Abo Akademi University.
- Felgen, J. (2004). A caring and healing environment. *Nursing Administration Quarterly*, 28(4), 288-301.

- Foss, B. & Naden, D. (2009). Janice Morse' theory of suffering – A discussion in a caring science perspective. *Vard I. Norden* 29(1), 14-18.
- Frank, A.W. (2001). Can we research suffering? *Qualitative Health Research*, 11(3), 353-362.
- Fredriksson, L.(1998). The caring conversation - Talking about suffering. A hermeneutic phenomenological study in psychiatric nursing. *International Journal for Human Caring*, 2(1), 24-32.
- Fredriksson, L., & Eriksson, K. (2001). The patient's narrative of suffering: A path to health? *Scandinavian Journal of Caring Science*, 15, 3-11.
- Georges, J. M. (2002). Suffering: Towards a contextual praxis. *Advances in Nursing Science*, 25(1), 79-86.
- Graber, D. R., & Mitcham, M. D. (2004). Compassionate clinicians. *Holistic Nursing Practice*, 18(2), 87-94.
- Gunderman, R. B. (2002). Is suffering the enemy? *Hastings Center Report*, 32(2), 40-44.
- Hallowell, N. (2006). Varieties of suffering: Living with the risk of ovarian cancer. *Health, Risk, and Society*, 8(1), 9-6.
- Imprint. (n.d.). In *Microsoft Encarta online dictionary*. Retrieved Oct. 20, 2009, from <http://www.encyarta.msn.com>
- International Bible Society. (1984). *The Holy Bible: The new international version*. Grand Rapids, MI: Zondervan.
- Isovaara, S., Arman, M., & Rehnsfeldt, A. (2006). Family suffering related to war experiences: An interpretative synopsis review of the literature from a caring science perspective. *Scandinavian Journal of Caring Science*, 20, 241-250.

- Jezuit, D. L. (2000). Suffering of critical care nurses with end-of-life decisions. *MEDSURG Nursing* 9(3), 145-153.
- Jezuit, D. (2003). Personalization as it relates to nurse suffering: How managers can recognize the phenomenon and assist suffering nurses. *JONAS Health-Care Law, Ethics, and Regulations*, 5(2), 25-28.
- Johansson, E., Roxberg, A., & Fridlund, B. (2008). Nurses' consolation: A grounded theory study. *Vard I. Norden*, 28(2), 19-22.
- Jonas-Simpson, C. (2007). Suffering: A critical phenomenon in nursing. *Nursing Science Quarterly* 20(3), 288-294.
- Kahn, D. L., & Steeves, R. H. (1986). The experience of suffering: Conceptual clarification and theoretical definition. *Journal of Advanced Nursing*, 11(6), 623-631.
- Kahn, D. L., & Steeves, R. H. (1995). The significance of suffering in cancer care. *Seminars in Oncology Nursing*, 11(1), 9-16.
- Katz, R. S., & Johnson, T. A. (2006). Suffering and the caring professional. In: Arbore, P., Katz, R. S., & Johnson, T. A. *When professionals weep: Emotional and countertransference responses in end-of-life care*. NY: Routledge, Taylor, & Francis Group, 13-26.
- Lahdesmaki, I., & Nyholm, L. (2007). Intensive care and Eriksson's theory of caritative caring in 2050. *Nursing Science Quarterly* 20(4), 332-335.
- Leininger, M. M. (1981). *Caring: An essential human need* (Ed.). *Proceedings of the three national caring conferences*. Thorofare, NJ: Charles B. Slack.

- Lindholm, L., & Eriksson, K. (1993). To understand and alleviate suffering in a caring culture. *Journal of Advanced Nursing*, 18,(9), 1354-1361.
- Lindholm, L., Holmberg, M., & Makela, C. (2005). Hope and hopelessness - Nourishment for the patient's vitality. *International Journal for Human Caring*, 9(4), 33-38.
- Lindstrom, U., Lindholm, L., & Zetterlund, J. (2006). Theory of caritative caring. In: Marriner, Tomey, A. & Alligood, M.R. (Eds). *Nursing theorists and their work (6th ed.)*. St. Louis, MO: Mosby-Elsevier, 191-223.
- Lohne, V. (2005). Patients' experiences of hope and suffering during the first year following acute spinal cord injury. *Journal of Clinical Nursing*, 14, 285-293.
- Maeve, M. K. (1998). Weaving a fabric of moral meaning: How nurses live with suffering and death. *Journal of Advanced Nursing*, 27, 1136-1142.
- Mayeroff, M. (1971). *On caring*. New York: Harper & Row.
- Melvin, C. S., & Heater, B. S. (2004). Suffering and chronic sorrow: Characteristics and a paradigm for nursing interventions. *International Journal for Human Caring*, 8(2), 41-47.
- Monin, J. K. & Schulz, R. (2009). Interpersonal effects of suffering in older adult caregiving relationships. *Psychology and Aging*, 24(3), 681-695.
- Morse, J. M. (1997). Responding to threats to integrity of self. *Advanced Nursing Science*, 19, 21-36.
- Morse, J. M. (2000). Responding to the cues of suffering. *Health Care for Women International*, 21, 1-9.

- Morse, J. M. (2001). Toward a praxis theory of suffering. *Advances in Nursing Science*, 24(1), 47-59.
- Morse, J. M., Bottorff, J., & Hutchinson, S. (1994). The phenomenology of comfort. *Journal of Advanced Nursing*, 20, 189-195.
- Morse, J. M., Bottorff, J., Anderson, G., O'Brien, B., & Solberg, S. (2006). Beyond empathy: Expanding expressions of caring. *Journal of Advanced Nursing* 53 (1), 75-90.
- Morse, J. M., & Carter, B. J. (1995). Strategies of enduring and the suffering of loss: Modes of comfort used by a resilient survivor. *Holistic Nursing Practice*, 9(3), 38-52.
- Morse, J. M., & Carter, B. J. (1996). The essence of enduring and expressions of suffering: The reformulation of self. *Scholastic Inquiry of Nursing Practice*, 10, 43-60.
- Moustakas, C. E. (1994). *Phenomenological research methods*. Thousand Oaks, CA: Sage.
- Murray, C. D., & Harrison, B. (2004). The meaning and experience of being a stroke survivor: An interpretative phenomenological analysis. *Disability and Rehabilitation*, 26(13), 808-816.
- Nouwen, H. J., McNeill, D. P., & Morrison, D. A. (1982). *Compassion: A reflection on the Christian life*. London: Durton, Longman, and Todd.
- Owens, D. A. (2005). Understanding suffering. *Journal of Hospice and Palliative Nursing*, 7(2), 68.

- Perry, B. (2009). Conveying compassion through attention to the essential ordinary. *Nursing Older People*, 21(6), 14-21.
- Polit, D. F., & Beck, C. T. (2006). *Essentials of nursing research: Methods, appraisal, and utilization*. Philadelphia: Lippincott, Williams, and Wilkins.
- Polit, D. F., & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice*. Philadelphia, PA: Wolters Kluwer/Lippincott, Williams, & Wilkins.
- Quinn, J. F., Smith, M., Ritenbaugh, C., Swanson, K., & Watson, M. J. (2003). Research guidelines for assessing the impact of the healing relationship in clinical nursing. *Alternative Therapies*, 9(3), A65-A79.
- Raholm, M. B., & Eriksson, K. (2001). Call to life: Exploring the spiritual dimension as a dialectic between suffering and desire experienced by coronary bypass patients.
- Raholm, M. B., & Lindholm, L. (1999). Being in the world of the suffering patient: A challenge to nursing ethics. *Nursing Ethics*, 6(6), 528-539.
- Raholm, M. B., Lindholm, L., & Eriksson, K. (2002). Grasping the essence of the spiritual dimension reflected through the horizon of suffering: An interpretive research synthesis. *The Australian Journal of Holistic Nursing*, 9(1), 4-13.
- Rawnsley, M. M. (1996). Response to "The essence of enduring and expressions of suffering: The reformulation of self." *Scholarly Inquiry for Nursing Practice: An International Journal* 10(1), 61-74.

- Redman, R. W., & Lynn, M. R. (2005). Assessment of patient expectations for care. *Research and Theory of Nursing Practice: An International Journal*, 19(3), 275-285.
- Rehnsfeldt, A., & Eriksson, K. (2004). The progression of suffering implies alleviated suffering. *Scandinavian Journal of Caring Science*, 18, 264-272.
- Rodgers, B. L., & Cowles, K. V. (1997). A conceptual foundation for human suffering in nursing care and research. *Journal of Advanced Nursing*, 25(5), 1048-1053.
- Rowe, J. (2003). The suffering of the healer. *Nursing Forum*, 38(4), 16-20.
- Smith, A. A. (2001). Concept analysis of healing in chronic pain. *Nursing Forum*, 36(4), 21-27.
- Smith, M. (1999). Caring and the science of unitary human beings. *Advances in Nursing Science*, 21(4), 14-28.
- Soderberg, A., Gilje, F., & Norberg, A. (1996). Meeting tragedy: Interviews about situations of ethical difficulty in intensive care. *Intensive and Critical Care Nursing*, 12(4), 207-217.
- Steeves, R. H., Kahn, D. J., & Benoliel, J. (1990). Nurses' interpretations of the suffering of their patients. *Western Journal of Nursing Research*, 12(6), 715-731.
- Sundin, K., Axelsson, K., Jansson, L., & Norberg, A. (2000). Suffering from care as expressed in the narratives of former patients in somatic wards. *Scandinavian Journal of Caring Sciences*, 14(1), 16-22.
- Swanson, K. (1991). Empirical development of a middle-range theory of caring. *Nursing Research* 40, 161-166.

- Swanson, K. (1999). What is known about caring in nursing science? In A.S. Hinshaw, S. Fleetham, & J. Shaver (Eds.), *Handbook of Clinical Nursing Research* (pp. 31-60). Thousand Oaks, CA: Sage.
- Tyler-Ball, S. (2007). Entering the between: Courage to attend to suffering. *International Journal of Human Caring*, 11(2), 81-83.
- von Dietz, E., & Orb, A. (2000). Compassionate care: A moral dimension of nursing. *Nursing Inquiry*, 7(3), 166-174.
- Watson, J. (1979). *The philosophy and science of caring*. Boston: Little, Brown & Co.
- Watson, J. (1985). *Nursing: Human science and human care: A theory of nursing*. Norwalk, CT: Appleton-Century-Crofts.
- Watson, J. (1999). *Nursing: Human science and human care, A theory of nursing*. Sudbury, MA: Jones and Bartlett & National League for Nursing.
- Watson, J. (2002). *Assessing and measuring caring in nursing and health science*. New York: Springer.
- Watson, J. (2005). *Caring science as sacred science*. Philadelphia: F.A. Davis.
- Wayman, L. M., & Barbato-Gaydos, H. L. (2005). Self-transcending through suffering. *Journal of Hospice and Palliative Nursing*, 7(5), 263-270.
- White, K., Wilkes, L., Cooper, K., & Barbato, M. (2004). The impact of unrelieved patient suffering on palliative care nurses. *International Journal of Palliative Nursing* 10(9), 438-444.
- Wiman, E., & Wikblad, K. (2004). Caring and uncaring encounters in nursing in an emergency department. *Journal of Clinical Nursing*, 13, 422-429.

Younger, J. B. (1995). The alienation of the sufferer. *Advances in Nursing Science* 17(4), 53-72.

Zuzelo, P. R. (2007). Exploring the moral distress of registered nurses. *Nursing Ethics*, 14(3), 344-359.

APPENDIX A

INTERVIEW SCHEDULE

Lived experiences of suffering of persons who have endured life-impacting events

Date of interview:

Time of interview:

Interview setting (describe):

Interviewer: Barb Braband

Field observations of interviewee: (May also collect journal of responses to questions if completed prior to interview or other personal items such as photos or letters – all personal items will be returned at conclusion of interviews).

Description of study: I am conducting a one-hour research interview with you today and one or more additional follow-up interviews with you to explore your experience with suffering. I will ask you several questions to learn more details about how suffering has impacted your life. Please read the consent form carefully and sign it. I will be happy to answer any questions you may have about this research study. I will audio-tape and possibly video-tape this interview and transcribe it following the interview. I will not allow the use of any identifying information to be included with the transcription of these interviews, journals, or personal items to protect your privacy.

Questions:

1. Tell me about your experiences with suffering. What types of suffering have you experienced?
 - a. Describe a time when you experienced suffering? What was it like for you? For others close to you? Was there a difference in your experience and your significant others' experience of suffering? Explain.
 - b. What feelings do you recall from that time?
 - c. Describe a time when you struggled the most during this experience.
2. How would you describe "enduring" or "getting through" suffering?
 - a. Is enduring suffering different from suffering? How?
 - b. How long have you endured some types of suffering in your life?
 - c. What support was helpful when you endured suffering? What wasn't helpful?
3. How has suffering impacted your life?
 - a. Tell me about your needs and struggles while you endured suffering? Physical, emotional, or spiritual struggles or needs?
 - b. What other related issues or concerns surfaced for you at this time?
 - c. Describe your perceptions about time through this period. What was it like for you? For others close to you?
4. Describe the support you received from others during your suffering experience.
 - a. How have others responded to you in your suffering experience?
 - b. What do you wish that others would have said or done for you during this time?
 - c. How did professional caregivers help you through your suffering? What did they fail to do for you? What did they do that wasn't helpful?
5. What are your perceptions of healing at this point in your experience of suffering?
 - a. What ways have you encountered healing through your suffering?
 - b. Do you see this healing as partial or complete?
6. What have you learned about yourself through this suffering?

Conclusion of interview: Thank you for participating in this interview. Your responses will be confidential. I will return your interview transcripts for you to review and verify for accuracy either through a private or focus group session; or by mail if needed. I will also return any personal items I may have taken for review.

APPENDIX B

DOCUMENTATION FROM COLLEGE OF SAINT MARY

INSTITUTIONAL REVIEW BOARD

Application for Research Approval

College of Saint Mary
Institutional Review Board

Before submitting the application, the researcher must determine whether a full review or exempt review is required by consulting CSM's IRB Guidelines, available from the IRB chair. The researcher must also follow the guidelines for submitting this Application, as outlined in the IRB Guidelines.

Full Review Exempt Review

- I. Purpose of the Study. Briefly identify the specific aim of the research – why is the research being conducted?

The purpose of this qualitative, phenomenological study is to describe the essence and meaning of the lived experiences of suffering for persons who have faced life-impacting adversity at various stages of their lives. The study is devoted to understanding the essence and meaning of the lived experiences of suffering by examining this question: *What is the lived experience for persons who have experienced life-impacting suffering?*

- II. Background and Rationale (Full Review only). What is the background and scientific rationale for the study? Include literature citation if relevant.

There has been a lack of focus on the phenomenon of suffering (White, Wilkes, Cooper, & Barbato, 2004) in relation to exploration of the deep meaning of suffering on persons' lives. This study is significant because it addresses the complexity of the impact of suffering in persons' lives. At this stage of the research, the concept of suffering will be generally defined as the "severe distress associated with events that threaten the intactness of the person" (Cassell, 1991). Through heightened awareness of the lived experience of suffering, caregivers may recognize more effective methods to enhance comfort and support for suffering persons.

- III. Number of Participants Expected.

The number of participants expected will include a total of four for this class research assignment.

- IV. Characteristics of Participants. What are the specific inclusion criteria for participation? If there are participation restrictions (e.g., gender, race, religion, age, etc.), provide rationale as to why these restrictions are necessary.

The inclusion criteria for participation includes persons age thirty or over, who have experienced the phenomenon of life-impacting suffering. There are no participation restrictions for gender, race, or religion. Rationale for the age restriction supports the greater probability of persons who have faced life-impacting suffering with the maturity to recognize the impact of suffering and their personal reactions to it.

V. Method of Participant Recruitment.

The method of participant recruitment is purposeful convenience criterion sampling strategies to find individuals who have experienced the phenomenon of life-impacting suffering who are willing to share these experiences.

VI. Study Site(s). Where will the study be conducted?

The study will be conducted in the local community of the student interviewers at a mutually agreed upon neutral site which provides a setting conducive to the participant's maximum comfort and confidentiality.

VII. Description of Procedures (Full Review only). Identify exactly what participants will be doing in your study, as well as what will be done to participants. Identify all procedures, including audio or video recording, or observation of the participant.

Research investigators will collect demographic data (age, gender, and race), conduct a semi-structured interview for one hour or less, audio-tape the interview, and transcribe the interview. Following the transcription of the interview, the investigators will send each participant a copy of their individual interview transcript (via e-mail or mail at their preference) for review and verification for accuracy (member check). Participants may be contacted for a potential future interview, pending the need for further information.

VIII. Confidentiality. Address how data will be kept confidential. Will any identifiers be used to specifically link data to an individual participant? If so, provide justification as to why identification of individuals is necessary.

Data will be kept confidential and locked in an office file cabinet. Audiotapes will be transcribed without any participant identifiers. Identifiers will not be used to specifically link data to an individual participant.

IX. Informed Consent (Full Review only). The form should include full disclosure of the study. See Informed Consent Guidelines for full information.

The informed consent will include full disclosure of the study. Participants will keep a copy of their signed consent form and the interviewer will also keep a copy.

**IRB#:****Title of this Research Study**

PHENOMENOLOGICAL EXPLORATION: LIVED EXPERIENCES FOR PERSONS WHO HAVE FACED LIFE-IMPACTING SUFFERING.

Invitation

You are invited to take part in this research study. The information in this form is meant to help you decide whether or not to take part. If you have any questions, please ask.

Why are you being asked to be in this research study?

You are being asked to be in this study because you have been identified as a person who has experienced life-impacting suffering.

What is the reason for doing this research study?

People who face suffering are impacted in many different ways. This research is designed to address the complexity of the suffering in persons' lives. Through heightened awareness of the lived experience of suffering, caregivers may recognize more effective methods to enhance comfort and support for suffering persons.

What will be done during this research study?

Your participation will involve completion of demographic data, a tape-recorded interview of approximately one hour, and a review (via e-mail or mailed copy) of the transcript of the interview to verify accuracy.

What are the possible risks of being in this research study?

Risks common to this type of behavioral research may include loss of confidentiality and emotional or psychological distress.

What are the possible benefits to you?

The possible benefits of this protocol may include enhanced personal awareness and understanding of the effects of the suffering experience in one's life. Your participation may benefit you through your knowledge of your contributions to support the advancement of enhanced understanding for the phenomenon of suffering for nursing and other healthcare professions. However, you may not get any benefit from being in the study.

What are the possible benefits to other people?

The possible benefits to society may include the advancement of knowledge for the impact of suffering in the human experience.

What are the alternatives to being in this research study?

Instead of being in this research study you can choose not to participate.

What will being in this research study cost you?

There is no cost to you to be in this research study.

Will you be paid for being in this research study?

You will not be paid or compensated for being in this research study.

What should you do if you have a problem during this research study?

Your welfare is the major concern of every member of the research team. If you have a problem as a direct result of being in this study, you should immediately contact one of the people listed at the end of this consent form.

How will information about you be protected?

Reasonable steps will be taken to protect your privacy and the confidentiality of your study data. Data will be kept confidential and locked in an office file cabinet. Audiotapes will be transcribed without any participant identifiers. Identifiers will not be used to specifically link data to an individual participant. The only persons who will have access to your research records are the study personnel, the Institutional Review Board (IRB), and any other person or agency required by law. The information from this study may be published in scientific journals or presented at scientific meetings but your identity will be kept strictly confidential.

What are your rights as a research subject?

You have rights as a research subject. These rights have been explained in this consent form and in the Rights of Research Subjects that you have been given. If you have any questions concerning your rights, talk to the investigator or call the Institutional Review Board (IRB), telephone (402)-

What will happen if you decide not to be in this research study or decide to stop participating once you start?

You can decide not to be in this research study, or you can stop being in this research study ("withdraw") at any time before, during, or after the research begins. Deciding not to be in this research study or deciding to withdraw will not affect your relationship with the investigator, or with the College of Saint Mary.

You will not lose any benefits to which you are entitled.

If the research team gets any new information during this research study that may affect whether you would want to continue being in the study, you will be informed promptly.

Documentation of informed consent

You are freely making a decision whether to be in this research study. Signing this form means that (1) you have read and understood this consent form, (2) you have had the consent form explained to you, (3) you have had your questions answered and (4) you have decided to be in the research study.

If you have any questions during the study, you should talk to one of the investigators listed below. You will be given a copy of this consent form to keep.

Signature of Subject: _____ Date: _____ Time: _____

My signature certifies that all the elements of informed consent described on this consent form have been explained fully to the subject. In my judgment, the participant possesses the legal capacity to give informed consent to participate in this research and is voluntarily and knowingly giving informed consent to participate.

Signature of Investigator: _____ Date: _____

Authorized Study Personnel

Principal Investigator:

Barb Braband
RN, MSN, MA
College of St. Mary student
Day phone number: 515-643-6722
E-mail: bbraband@mercydesmoines.org

Secondary Investigator:

JoAnn Olson
RN, MSN, ARNP
College of St. Mary Student
Day phone number: 515-643-
E-mail: jolson@mercydesmoines.org

APPENDIX C

MEMBER CHECK CONFIRMATION LETTER

Date

Dear <Name>

Thanks so much for participating in the research interviews on <insert date>. I greatly appreciate your willingness to share your insights on the study entitled: “The Suffering Journey: Lived Experiences For Persons Who Have Faced Life-Impacting Suffering.”

Enclosed you will find a verbatim transcript of our conversation for you to review. As part of the research process, it is important that participants confirm the accuracy and completeness of our conversation. Please read the manuscript, make any changes or corrections, and mail back to me in the pre-addressed, pre-paid envelope. If you do not need to make any changes please return this form in the pre-addressed, pre-paid envelope. Your signature confirms the receipt of the transcript and acknowledges your belief that the transcript is a complete and accurate portrayal of our conversation. I would appreciate the return of the corrections or confirmation by <insert date>.

Again, thank you for your time and effort in participating in this research study. Your input is important. Please let me know if you have any questions or comments.

Sincerely,

Barb Braband

<add all contact information>

I, _____, acknowledge receipt of the verbatim transcript of my
(please print your name)
 interview with Barb Braband for the research study: “The Suffering Journey: Lived Experiences For Persons Who Have Faced Life-Impacting Suffering.” My signature indicates I believe the transcript to be an accurate and complete account of our conversation.

 (Signature)

 (Date)

Appendix D

Audit Trail Letter

October 27, 2009

Barbara Braband has requested a qualitative research audit on her dissertation entitled “The Suffering Journey: Lived Experiences of Persons Who Have Endured Life-Impacting Suffering Events.” The purpose of this audit was to determine the degree to which the results of the study are trustworthy. The qualitative research audit was conducted from January 2009 through October 2009 and concluded on October 27, 2009.

An audit trail is conducted to provide accountability outlining the research process and the systematic thematic analysis (Miles & Huberman, 1984; Huberman & Miles in Deglin and Lincoln 1994; Lincoln and Guba 1985; Moustakas, 1994)

The audit was conducted by taking the following six steps:

1. Listened to audiotapes and examined verbatim transcripts (completed by peer reviewer).
 - a. Listened to taped conversation and read transcriptions.
 - b. Checked for added, omitted, or incorrect or inverted words.
 - c. Findings: Transcription errors were negligible. There were no errors that affected or altered the meaning of data. Therefore, the effect of transcription error or data analysis is deemed non-existent.
2. Reviewed researcher’s (s’) notes and materials
 - a. Institutional Review Board application and approval
 - b. Coded transcriptions
 - c. Researcher’s notes
 - d. Coding notes
 - e. Dissertation draft
 - f. Interview guide
 - g. Findings: The files included the required information and approval forms.
3. Reviewed participants’ consent forms
 - a. Signed forms were consistent with approved forms by the Institutional Review Board
 - b. Findings: All participants signed and gave consent to participate in the study.
4. Reviewed coding processes
 - a. Researcher’s notes indicated a transparent decision making trail of horizontalization and categorical aggregation.

- b. Findings: Data supported the identified theme.
- 5. Read draft dissertation
 - a. Report was read in its entirety with careful review of purpose, design, verification of data quality, and use of theory.
 - b. Findings: Theory and literature were described accurately. Ample description and direct quotes were consistent with the identified themes.
- 6. Reviewed purpose of this audit
 - a. The overall product and process was reviewed.
 - b. Findings: Appropriate procedures were utilized in producing the conclusions and findings. The data were accurately reported.

Based on the process outlined by Creswell (2007) the following conclusion is made:

Conclusion

In my opinion the study, *The Suffering Journey: Lived Experiences of Persons Who Have Endured Life-Impacting Suffering Events*, followed established processes for qualitative studies. This study remained consistent with its intended purpose statement, Institutional Review Board approval, and proposal as approved by the Dissertation Committee. The researcher's steps were clearly transparent and documented. Data were logically analyzed and supported by quotes from informants. Procedures were followed as outlined. There was evidence of the following activities: prolong engagement, member check, thick and rich descriptions, and transparent audit trail. The utilization of Moustakas (1994) method of qualitative analysis lends credibility to the findings and conclusions.

In summary, the researcher satisfied the criteria for dependability and confirmability of findings.

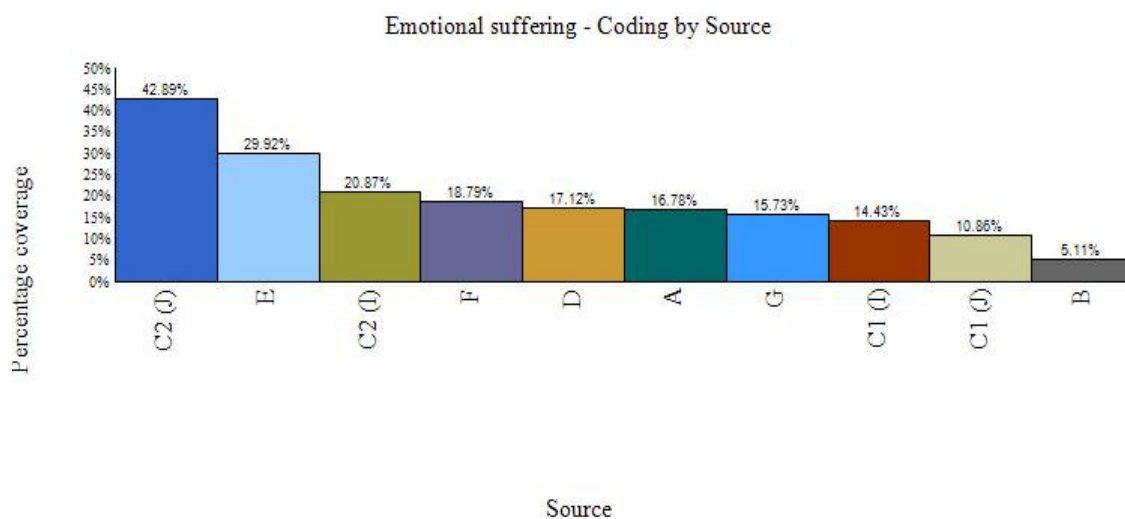
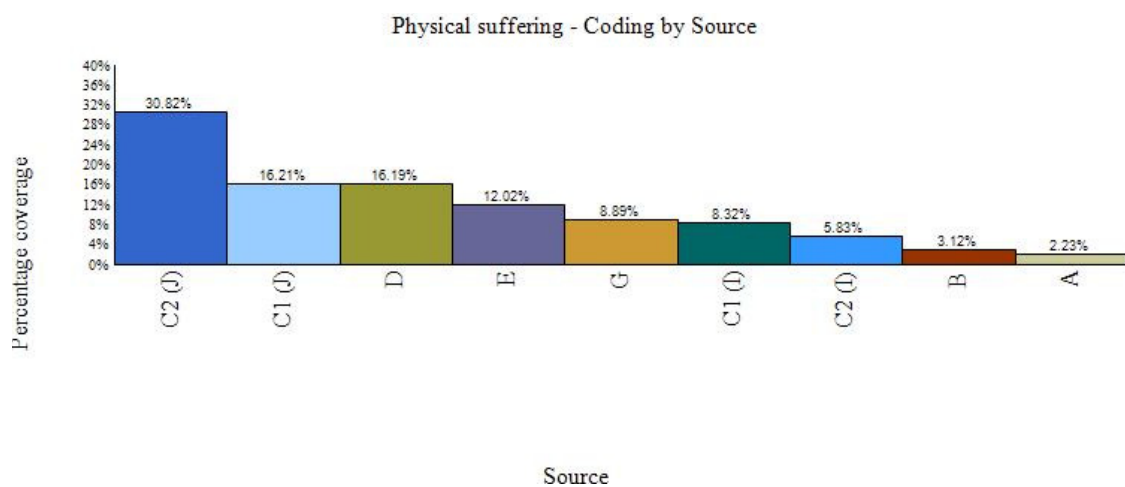
Attested to this 27th day of October in the year 2009.

Sincerely,

Peggy L. Hawkins, PhD, RN, BC, CNE
Professor
College of Saint Mary
7000 Mercy Road
Omaha, NE 68106

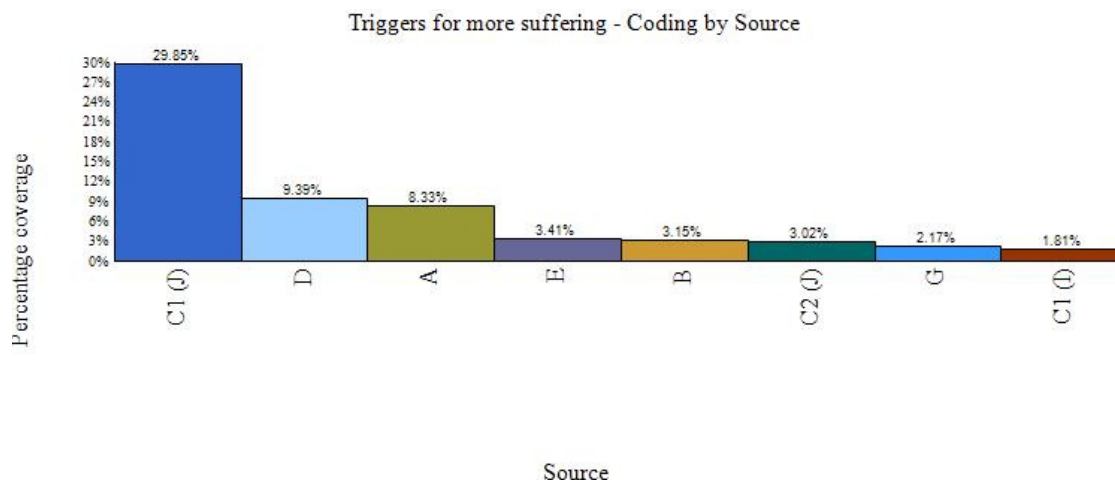
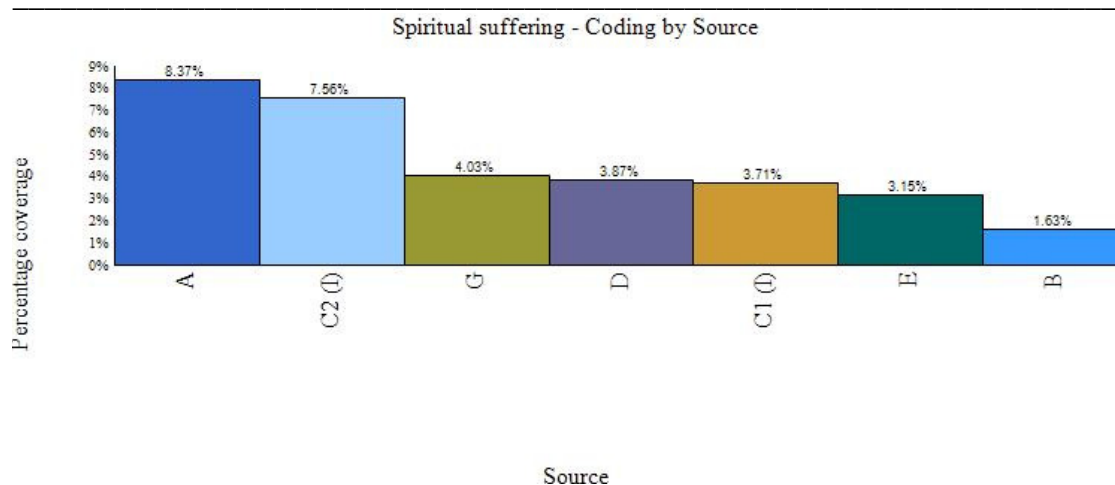
APPENDIX E

MAJOR THEMES: SUB-THEME CHARTS

Figure D1. Nature of suffering: emotional suffering.*Figure D2.* Nature of suffering: physical suffering.

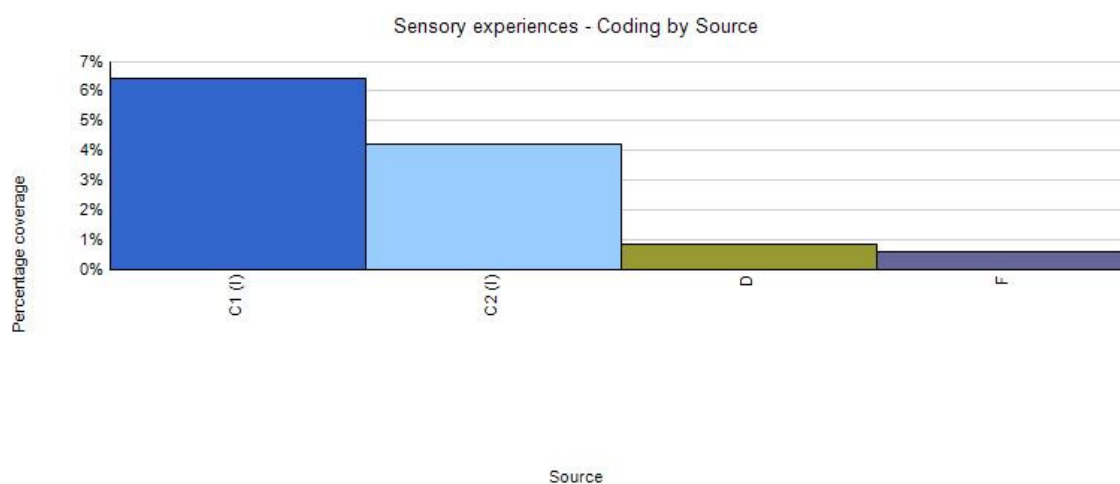
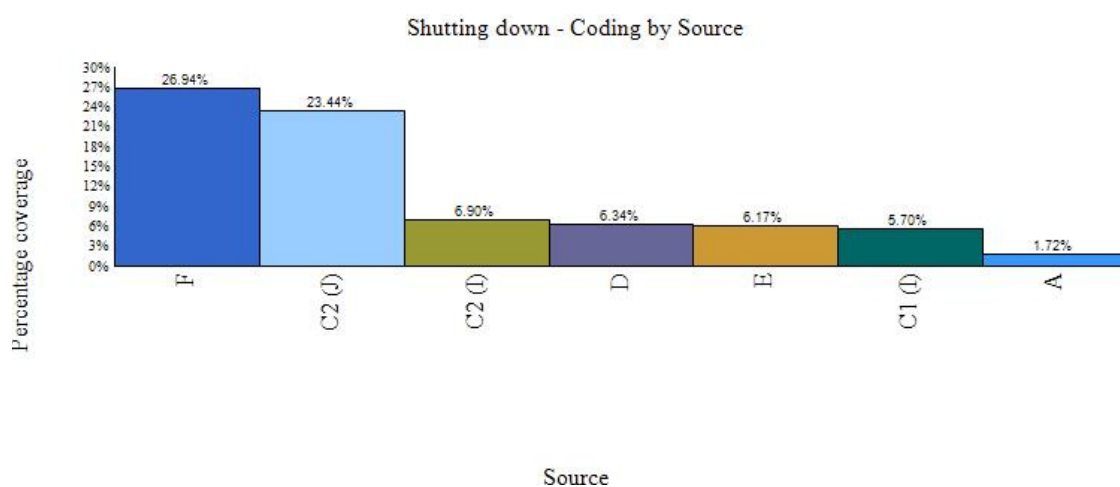
APPENDIX E

MAJOR THEMES: SUB-THEME CHARTS

Figure D3. Nature of suffering: triggers for more suffering.*Figure D4.* Nature of suffering: spiritual suffering.

APPENDIX E

MAJOR THEMES: SUB-THEME CHARTS

Figure D5. Nature of suffering: sensory experiences.*Figure D6.* Enduring: shutting down.

APPENDIX E

MAJOR THEMES: SUB-THEME CHARTS

Figure D7. Enduring: isolation – longing for help.

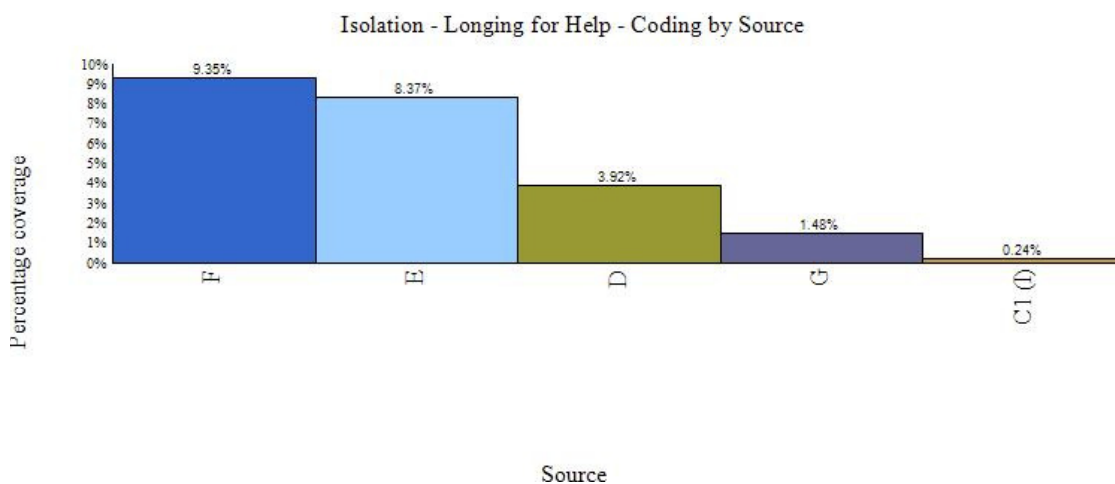
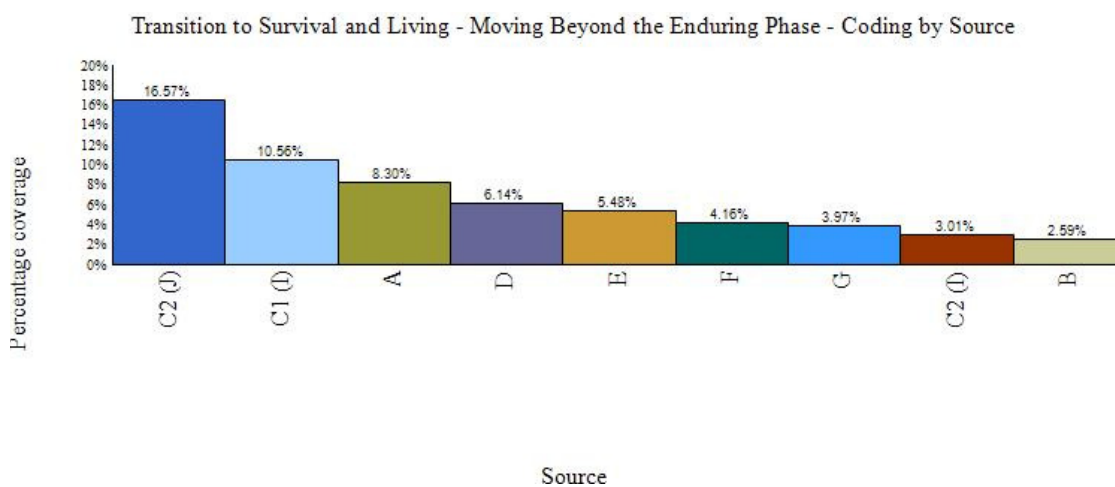


Figure D8. Enduring: transition to survival and living – moving beyond the enduring phase.



APPENDIX E

MAJOR THEMES: SUB-THEME CHARTS

Figure D9. Care and support: effective care and support from family and friends.

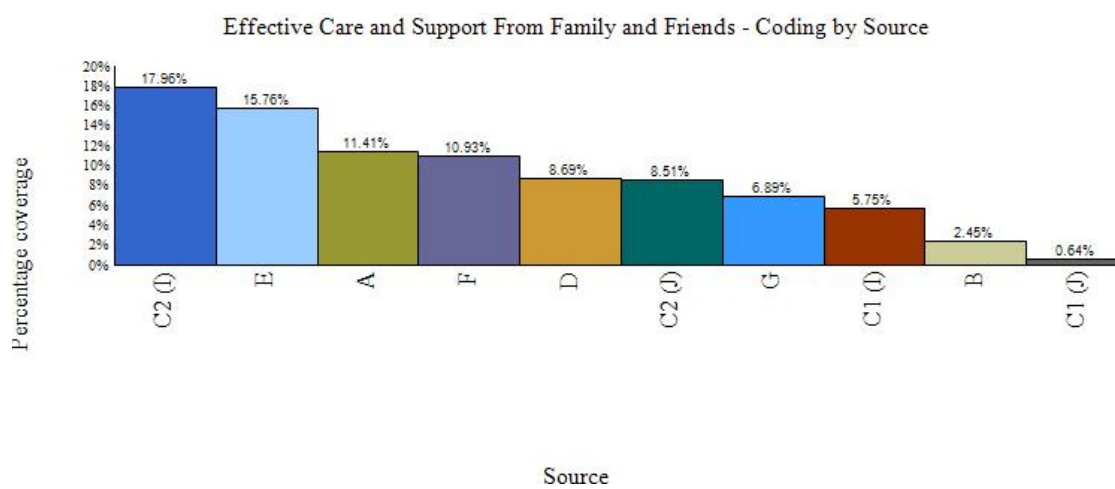
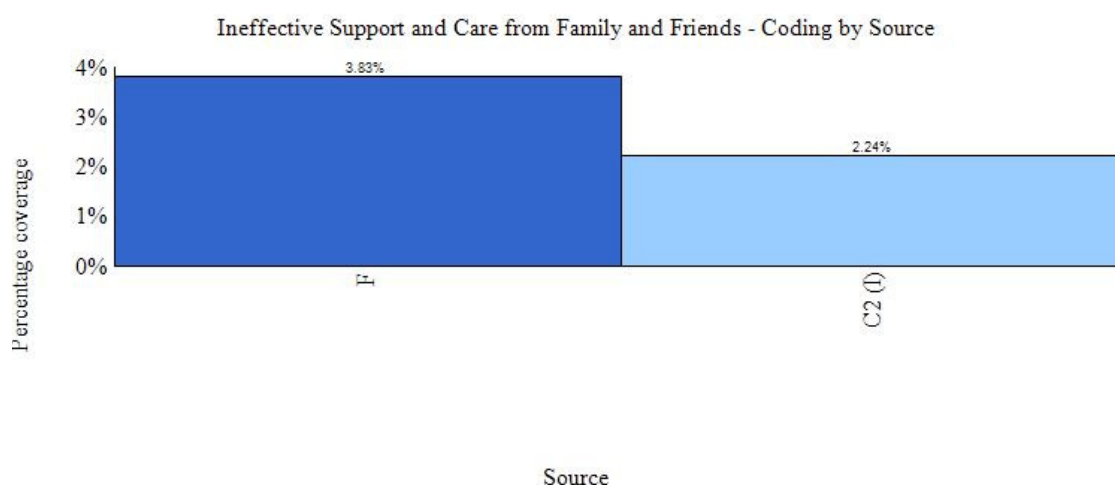


Figure D10. Care and support: ineffective support and care from family and friends.



APPENDIX E

MAJOR THEMES: SUB-THEME CHARTS

Figure D11. Care and support: effective professional care and support.

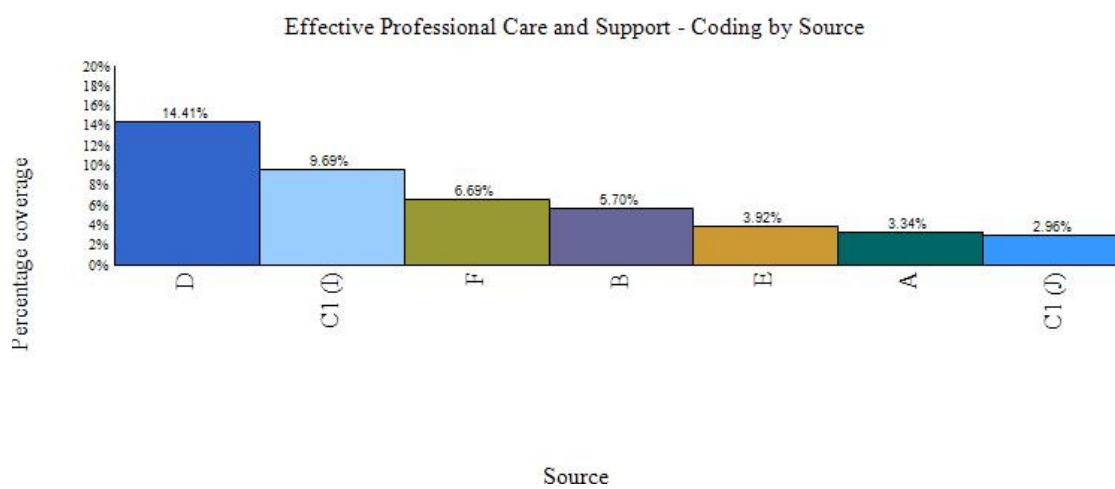
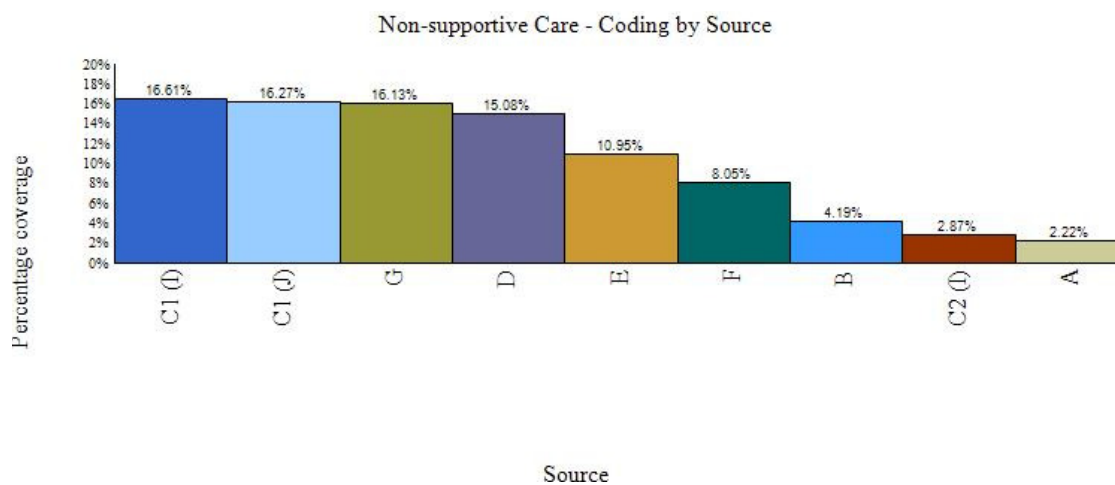


Figure D12. Care and support: Ineffective support from professional caregivers, non-supportive care.



APPENDIX E

MAJOR THEMES: SUB-THEME CHARTS

Figure D13. Family issues: decision-making in suffering and its impact on family.

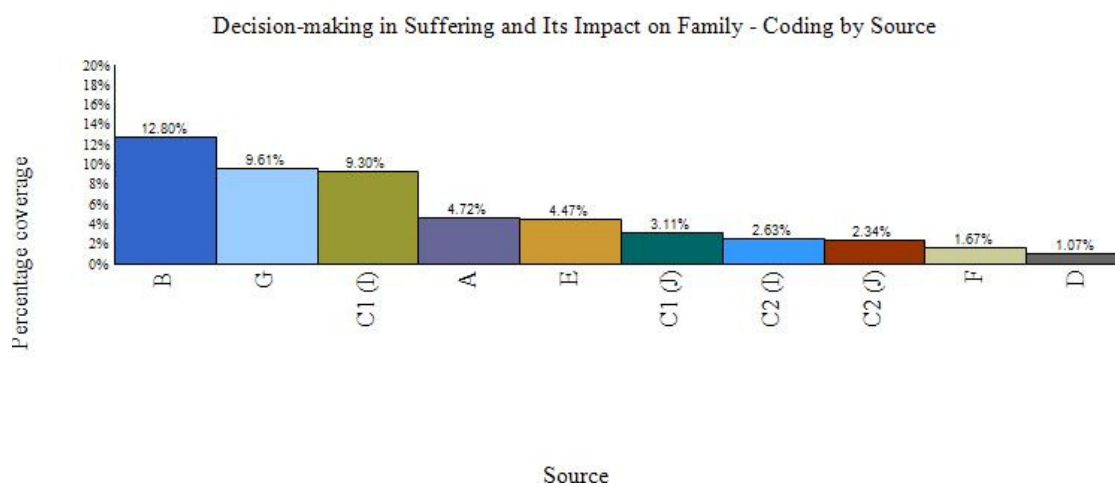
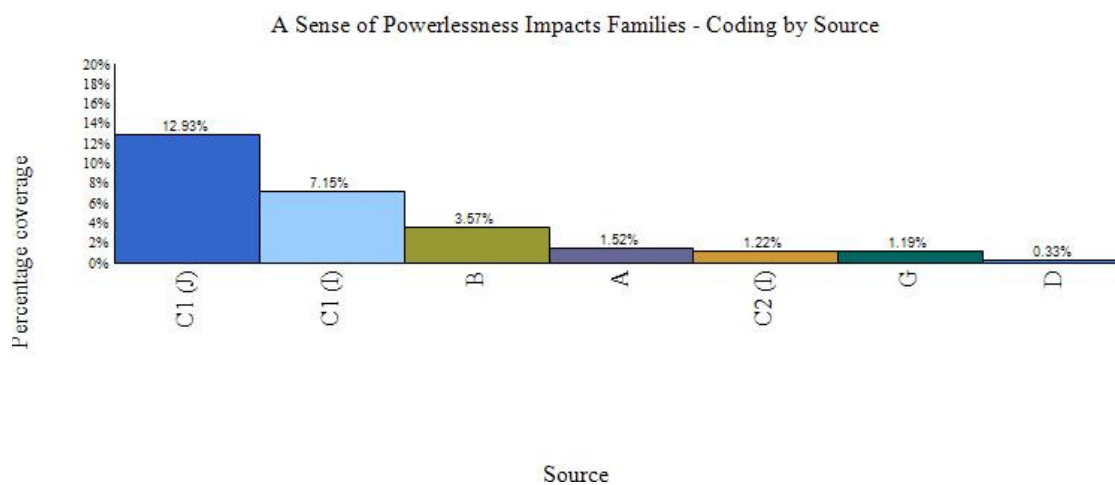


Figure D14. Family issues: a sense of powerlessness impacts families.



APPENDIX E

MAJOR THEMES: SUB-THEME CHARTS

Figure D15. Family issues: parallel suffering.

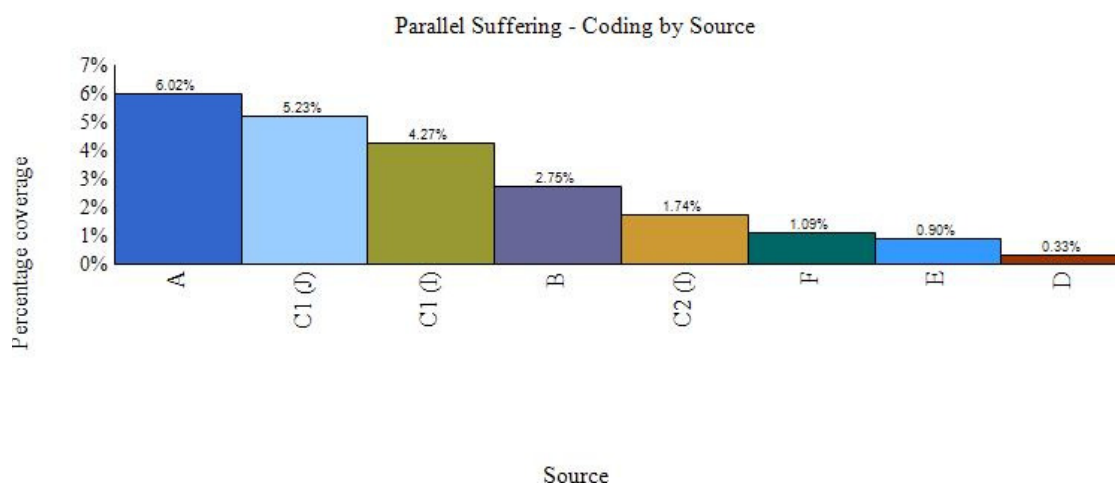
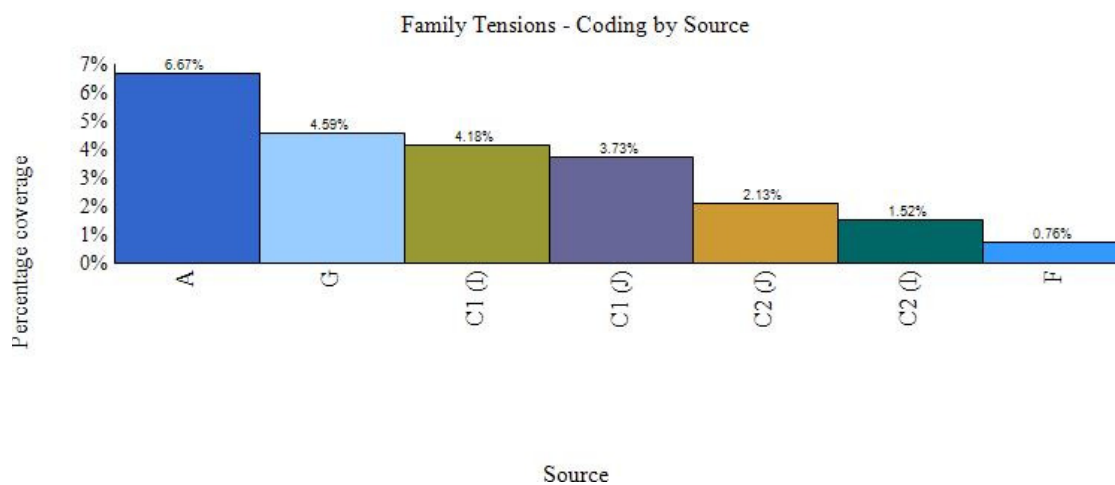


Figure D16. Family issues: family tensions.



APPENDIX E

MAJOR THEMES: SUB-THEME CHARTS

Figure D17. Beyond suffering – recovery and healing: adapting to changes.

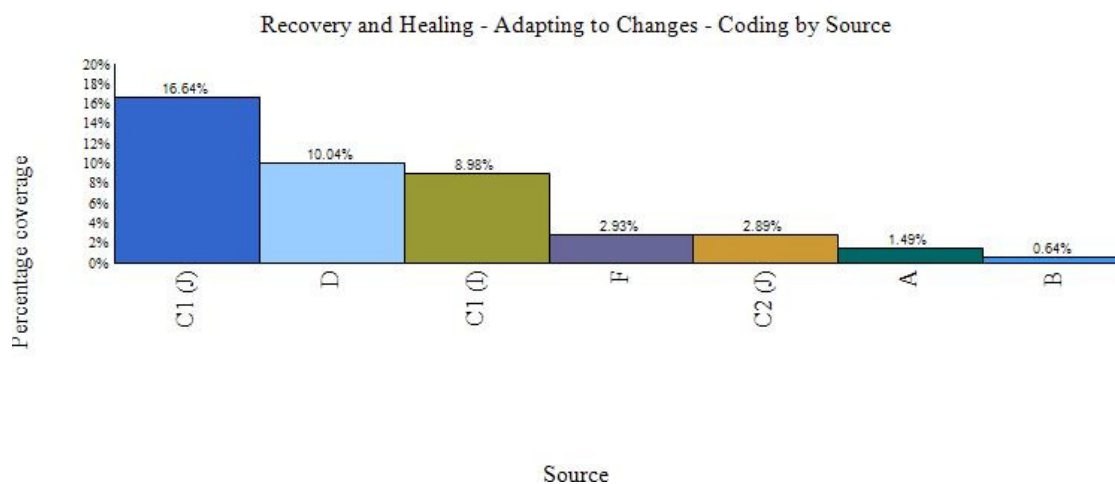
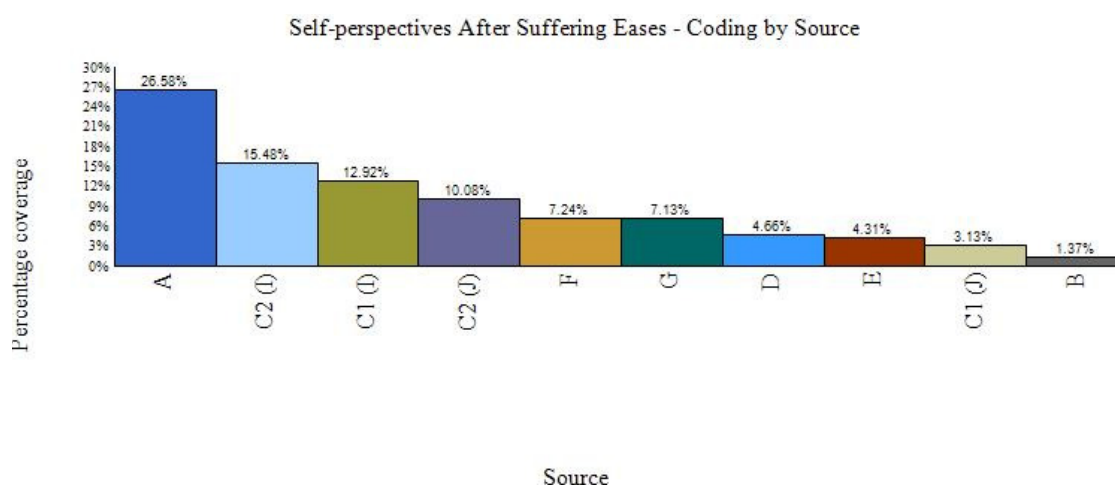


Figure D18. Beyond suffering – recovery and healing: self-perspectives after suffering eases.



APPENDIX F

SUFFERING INTERVIEW PROJECT

Directions: You will conduct a 1:1 personal interview with a person whom you know is currently enduring physical, emotional, and/or spiritual suffering. This person can be a member of your family, a friend, or an acquaintance. Be sure to protect the confidentiality of this person's identity. You will arrange to meet privately with this person for three sessions for a minimum of at least 30 – 45 minutes/session.

Assignment objectives:

- 1) Establish professional rapport (trust) and presence with the interviewee. Gain comfort in your communication skills.
- 2) Realize some of the overwhelming needs and issues of a suffering person.
- 3) Learn new and meaningful caring behaviors that apply to persons who suffer.
- 4) Examine sources of hope and how to maintain it during suffering

The assignment includes 2 parts:

- 1) Three separate interview sessions of 30-45 min./session. Focused, specific questions are given for each session. Be sure to have your interviewee sign their initials and date for each session. The written part of this assignment is to type a summary of responses for each question for each interview session and personal reflection questions which is worth a total of 40 points. Be sure to include the question with each response. A guideline of required questions is included.
- 2) Class presentation of selected portions of your interview summary and personal reflection of what you have learned during the process of the interview. This is worth a total of 10 points.

How to use the interview question guidelines:

- 1) The goal of the interview is to focus on the content of the questions. Your individual style of communication may affect how you pose the questions, but the content is very important. The interviewee may answer questions before you ask them, so listen carefully. You may also need to repeat, rephrase questions, or come back to tough questions, so try to be flexible and open-ended in your approach.
- 2) A tape recorder may be helpful so that you can record responses later without interruptions. Be sure to obtain permission from your interviewee to record their responses and assure them that they will remain confidential.
- 3) Don't share the guidelines with the interviewee. The designed format is an interview, not a form for them to complete on their own.

Session # 1Focus of this interview session:

- a) Build trust and rapport.
- b) Get comfortable in a professional relationship.
- c) Focus on the onset or beginning aspects of the person's suffering experience.

Getting started:

1. Introduce yourself.
2. Explain the purpose of the interview sessions. The goal of this project is to:
 - a. establish trust and build a relationship with a person who is experiencing suffering
 - b. realize some of the overwhelming needs and issues of a suffering person
 - c. learn what caring behaviors are helpful and meaningful for the one who suffers.
 - d. examine sources of hope and how to maintain it during suffering

Interview Questions: (Responses to these will be included in your summary)

Note: Don't ask the information in parentheses, these are helpful notes for you.

1. Tell me your story of when your suffering or struggle began. (Encourage the person to talk with as little interruption from you as possible – you will need to listen very carefully and clarify what you don't hear, understand, or forget as they talk to you).
2. Describe when it first started. What was it like for you? For others close to you?
3. What feelings do you recall from that time? Were there feelings of shock, denial, or other feelings?

Personal reflection: (include this in your summary)

1. How do you feel about the interview as a whole? Don't worry if your response is not all positive in nature.
2. Describe your comfort level with your communication skills and starting this interview.
3. What did you learn about the person's suffering experience that was upsetting to you?
4. Other comments: (optional)

Session #2Focus of this interview session:

- a) Re-establish trust and rapport.
- b) Discover the overwhelming needs and issues of a suffering person.

Getting started:

Note: Don't ask the information in parentheses, these are helpful notes for you.

1. How have you been since we last met?
2. Share a little of your reaction to their responses from Session #1 and a summary to set the stage for this session. (It's a quick summary to show that you listened and helps to build trust).
3. Today I'd like to explore some of the needs and issues you've encountered during your suffering experience.

Interview Questions: (Responses to these will be included in your summary)

1. Describe a time of crisis when you struggled the most during this experience.
2. Tell me about your needs and struggles:
 - a. Physical needs (body) – (note acute and chronic physical complaints or symptoms)
 - b. Emotional/mental needs (mind) (might be isolation, depression, anger, anxiety, etc)
 - c. Spiritual (spirit) – (might be depression, feeling cut off from faith/God, anger at God, hopelessness)
3. Tell me other issues or concerns that you've encountered. (could be financial, work interruptions or disability, change in family role, etc.) Which issues were the most overwhelming?

Personal reflection: (include this in your summary)

1. How did this interview go? Was it easier or more difficult than last time?
2. What are you learning about suffering?
3. What jumps out at you after this session?
4. Other comments:

Session #3Focus of this interview session:

- a) Re-establish trust and rapport.
- b) Learn new and meaningful caring behaviors for those who suffer

Getting started:

1. How have you been? Ask about their current condition.
2. Share a little of your reaction to their responses and a summary from Session #2 to set the stage for this session. (It's a quick summary to show that you listened and helps to build trust)
3. Today I'd like to discuss what others around you have done to show that they care about you and how you have maintained a sense of hope in your suffering.

Interview Questions: (Responses to these will be included in your summary)

1. How have others supported you? Explain what caring words and actions have been the most meaningful to you?
2. What was missing that you needed? What do you wish that others would have said or done for you?
3. What gives you a sense of hope when you're in pain? Have you ever lost a sense of hope? What triggered it?
4. What have you learned about yourself through this suffering?

Terminating the interview relationship:

1. Thank your interviewee for their time and help in the interview.
2. Offer a brief summary of their comments to all sessions if possible.
3. Follow-up with a call or visit in a few weeks to see how they are doing. You may be prompted to stay in touch and continue to develop a caring relationship on your own. That would be a true gift of service and compassion.

Personal reflection: (include this in your summary)

1. How do you feel about your communication skills now? How does it compare to the first and second sessions.
2. Describe how you feel about the relationship you've shared with this person.
3. What have you learned about suffering from this person? (give a minimum of 3 things)
4. What have you learned about maintaining a sense of hope during suffering?
5. What have you learned about caring behaviors that you will apply to your clinical practice with clients?
6. Other comments: